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FALLS IN WHEELCHAIR USERS WITH SPINAL CORD INJURY - INCIDENCE, RISKS AND CONCERNS

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FALLS IN WHEELCHAIR USERS WITH SPINAL CORD INJURY- INCIDENCE, RISKS AND CONCERNS THESIS FOR DOCTORAL DEGREE (Ph.D.)

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ABSTRACT

Background: Knowledge about falls and related injuries in persons with spinal cord injuries (SCI) is limited, especially concerning wheelchair users. Further research is required in order to develop future prevention programs, as falls seem to be common and may have serious consequences for persons with SCI.

Aims: to identify the incidence of falls and recurrent falls (>2 falls), and the incidence and severity of fall-related injuries in wheelchair users with SCI. Further, to investigate the validity of instruments for concerns about falling -SCI Falls Concern Scale (FCS), and fall risk prediction during one year with Downton Fall Risk Index and a question of falls the previous year.

Method: 224 persons with traumatic SCI were consecutively recruited at regular follow-up at Rehab Station Stockholm / Spinalis, Sweden and Sunnaas Rehabilitation Hospital, Norway. Inclusion criteria: ≥ 18 years old, ≥ 1 year post SCI. Exclusion criteria: persons with motor complete injuries above C5. Independent variables: demographic data, previous falls, quality of life, risk willingness, functional independence, and exercise habits. Falls were prospectively reported by text messages every second week for one year and were followed-up by telephone interviews. Outcomes: incidence of falls and related injuries, risk indicators for recurrent falls and injuries. SCI-FCS was translated to Swedish and tested for validity.

Results: The Swedish version of SCI-FCS showed, in general, similar psychometric properties as the original version supporting the validity of the scale. The wheelchair users reported overall low levels of concerns about falling. Pushing wheelchair in difficult situations caused most concerns.

Ambulatory persons reported more retrospective falls than wheelchair users, and mode of mobility had the highest odds ratio (OR) (2.9), for reporting recurrent falls. Ability to get up from the ground (OR=2.2) and performing regular exercise (OR=1.9) increased the OR of recurrent falls for the total sample, while higher age (OR=0.96 per increasing year of age) decreased the OR of recurrent falls. Associated factors differed between wheelchair users and ambulatory persons. Sixty-four percent fell and 32% fell recurrently, when the wheelchair users reported falls prospectively during one year. Recurrent falls previous year increased the OR of recurrent falls the following year (OR=10.2), and higher quality of life reduced the OR of fall-related injuries. In total, 70 fall-related injuries were registered, of which 47 (67%) were minor, 16 (23%) moderate and 7 (10%) were severe, and 34% reported at least one injury. Most falls occurred during transfers.

Downton Fall Risk Index had low accuracy for predicting falls in wheelchair users while the question of falls the previous year was more accurate (sensitivity 37 and 86%, respectively).

Conclusion: Falls were common, and ambulatory persons fell more than wheelchair users. In spite of a broad perspective on contributory factors, previous falls was the only significant risk indicator for recurrent falls in the wheelchair users. SCI-FCS showed promising validity. Downton Fall Risk Index could not predict those who fell, while the question of falls previous year was more accurate.

SAMMANFATTNING

Bakgrund: Kunskapen om fall och fallskador hos personer med ryggmärgsskador (RMS) är begränsad, speciellt vad gäller rullstolsbrukare. Eftersom fall och fallskador verkar vara vanliga, och kan få svåra konsekvenser för personer med RMS, så behövs vidare forskning för att utveckla preventionsprogram för fall och fallskador

Syfte: Det övergripande syftet var att identifiera förekomsten av fall, återkommande (>2) fall och fallskador, liksom bidragande orsaker till, och riskfaktorer för, återkommande fall och fallskador hos personer med RMS, framförallt de som använder rullstol. Vidare, att undersöka validiteten för en skala som mäter oro för att falla hos rullstolbrukare -Spinal Cord Injury Falls Concern Scale (SCI-FCS), och två metoder för fallprediktion under ett år (Downton Fall Risk Index och en fråga om fall föregående år).

Metod: 224 personer med kronisk traumatisk RMS rekryterades konsekutivt vid sina ordinarie årskontroller på Rehab Station Stockholm / Spinalis i Sverige och Sunnaas Rehabiliteringssjukhus i Norge. Inklusionskriterier: ≥ 18 år, ≥ 1 år sedan RMS. Exklusions-kriterier: personer med motoriskt kompletta skador ovan C5. Oberoende variabler var t.ex. demografiska data, tidigare fall, livskvalité, risktagande, funktionell självständighet och träningsvanor. Fall registrerades prospektivt med sms varannan vecka i ett år och följdes upp med telefonintervjuer. Beroende variabler var fallincidens, riskindikatorer för återkommande (> 2) fall och fallskador. SCI-FCS översattes till svenska och validitetstestades.

Resultat: De gående personerna rapporterade fler retrospektiva fall än rullstolsbrukarna, och förflyttningssätt (gå eller köra rullstol), var den faktor som hade högst odds ratio (OR) 2.9 för återkommande fall. Förmåga att ta sig upp från golvet (OR=2.2), regelbunden träning (OR=1.9) och lägre ålder (OR=0.96 per års ökad ålder), ökade också OR för återkommande fall. Olika faktorer var associerade med återkommande fall för rullstolsbrukarna och de gående personerna.

När rullstolsbrukarna rapporterade fall prospektivt under ett år så föll 64% och 32% föll återkommande. Återkommande fall under förra året ökade OR för återkommande fall följande år (OR=10.2) och högre livskvalité minskade OR för fallskador. Totalt registrerades 70 fallskador, varav 47 (67%) var mindre, 16 (23%) var måttliga och 7 (10%) var svåra, 34% rapporterade minst en skada. De flesta föll vid förflyttningar.

Den svenska versionen av SCI-FCS visade likvärdiga egenskaper som originalet vilket stödjer validiteten. Rullstolsbrukarna rapporterade generellt låg oro för att falla. Downton Fall Risk Index kunde inte predicera fall hos rullstolsbrukare (sensitivitet 37%), medan frågan om fall föregående år var mer exakt (sensitivitet 86%).

Konklusion: Fall var vanligt och gående personer föll mer än rullstolsbrukare. Tidigare fall var den enda riskfaktorn för återkommande fall hos rullstolsbrukarna. Downton Fall Risk Index kunde inte predicera de som föll, och SCI-FCS visade lovande validitet och att rullstolsbrukarna inte var speciellt oroliga för att falla

LIST OF SCIENTIFIC PAPERS

I. Butler Forslund E, Roaldsen KS, Hultling C, Wahman K and Franzén E. *Concerns about falling in wheelchair users with spinal cord injury—validation of the Swedish version of the spinal cord injury falls concern scale.* Spinal Cord. 2016 Feb;54(2):115-119

II. Jørgensen V*, Butler Forslund E*, Franzén E, Opheim A, Seiger Å, Ståhle A, Hultling C, Stanghelle JK, Wahman K and Skavberg Roaldsen K. *Factors associated with recurrent falls in individuals with traumatic spinal cord injury: a multicenter study.* Arch Phys Med Rehabil. 2016 Nov;97(11):1908-1916. *Shared first authorship.

III. Butler Forslund E, Jørgensen V, Franzén E, Opheim A, Seiger Å, Ståhle A, Hultling C, Stanghelle JK, Roaldsen KS and Wahman K. *High incidence of falls and fall-related injuries in wheelchair users with spinal cord injury: A prospective study of risk indicators.* J Rehabil Med 2017; 49: [Epub ahead of print] doi: 10.2340/16501977-2177

IV. Butler Forslund E, Skavberg Roaldsen K, Hultling C, Wahman K, Franzén E. *Predictors of falls in wheelchair users with spinal cord injury – a prospective study using the Downton Fall Risk Index and a single question of previous falls.* [In manuscript, may undergo changes before publication]

Associated paper

Jørgensen V, Butler Forslund E, Opheim A, Franzén E, Wahman K, Hultling C, Seiger Å, Ståhle A, Stanghelle JK, Skavberg Roaldsen K. *Falls and fear of falling are predictors of future falls and related injuries in ambulatory individuals with spinal cord injury: a longitudinal observational study*. [Accepted]

CONTENTS

LIST OF ABBREVIATIONS

AISA	American Spinal Injury Association
AIS	ASIA Impairment Scale
CI	Confidence interval
FCS	Falls Concern Scale
FES-I	Falls Efficacy Scale International
HR	Hazard ratio
ISNCSCI	International Standards for Neurological Classification of Spinal Cord Injury
KI	Karolinska Institutet
MS	Multiple sclerosis
OR	Odds ratio
ProFaNe	Prevention of Falls Network Earth, (formerly Europe)
Rehab Station /Spinalis	Rehab Station Stockholm / Spinalis SCI unit
SCI	Spinal cord injury
SCIM	Spinal Cord Injury Independence Measure
SCIP Falls study	Spinal Cord Injury Preventions of Falls study
SD	Standard deviation
Sms	Short message service (text-message)
Sunnaas	Sunnaas Rehabilitation Hospital

1 INTRODUCTION

1.1 FOREWORD

Spinal Cord Injury Prevention of Falls (SCIP Falls) study is a joint venture between Rehab Station Stockholm, Sweden, Sunnaas Rehabilitation Hospital, in Nesodden outside Oslo, Norway, and Karolinska Institutet, Sweden. The long-term goals of this study are to prevent falls, fall- related injuries and negative consequences of falls in persons with spinal cord injury (SCI). At the time of planning and execution of the study, in 2012, the research field concerning falls after SCI was rather new, but since then other research groups have joined and started to broaden the knowledge base. In addition, studies concerning falls in persons with other neurological diagnoses such as multiple sclerosis (MS), Parkinsons disease and polio have emerged, showing that adults who are not yet elderly have increased risk of falling compared to person's with-out neurological diagnoses.

When asked to join the SCIP Falls study, my first reaction was; why measuring falls after SCI, don't they have more important problems? And, more mindboggling and redundant, if you fall with-out getting injured, is that even a problem? After thinking a while I realized that I could not answer those questions without performing the study, which made me decide to go ahead. However, earlier studies have been focusing mainly on ambulatory persons, and as a physiotherapist in the SCI-field I wanted to contribute to reduce the gap of knowledge especially in wheelchair users.

This thesis consists of four parts: one retrospective paper concerning incidence and risk factors for recurrent falls in both ambulatory persons and wheelchair users (paper 2), and one prospective paper concerning incidence and risk factors for recurrent falls and fall-related injuries in wheelchair users (paper 2). Further, it comprises two validation papers based on wheelchair users, one regarding assessment of concerns about falling (paper 1), and one regarding fall risk assessment (paper 4). The main focus in this thesis has been on wheelchair users, and results regarding the ambulatory persons have been presented in the thesis "Falls in ambulatory persons with SCI, incidence, risk factors and perceptions of falls", by my fellow PhD candidate in the Norwegian setting, Vivien Jørgensen, at Karolinska Institutet 2016.

1.2 SPINAL CORD INJURY

Immediately following a spinal cord injury (SCI), life changes for both the survivor and his/hers family. It is an overwhelming situation with severe physical and psychological challenges. Concerning physical status, one could expect a varying degree of deficit, ranging from a very discrete reduction in function to total paralysis. This is because the spinal cord is responsible for the communication between the brain and different parts and functions of the body, and the SCI causes an immediate reduction in motor and sensory function. Accordingly, the consequences of a SCI vary depending on the level and extent of the lesion.

1.2.1 Level and extent of injury

The level of SCI is determined by the site of injury, i.e. cervical, thoracic, lumbar or cauda equine, while the extent refers to the completeness of lesion. A cervical injury results in tetraplegia (C1-C8), causing reduced motor and/ or sensory function in all four extremities, as well as in the trunk and the inner organs. An injury to the thoracic (Th1-Th12), lumbar (L1-L5) or sacral (S1-S5), parts of the spinal cord results in paraplegia, affecting the legs, and to a varying extent, the trunk and inner organs. Paraplegia also includes injuries to the conus medullaris and the cauda equine (1). The proportion of tetraplegia is between 44 and 57% (2-4).

A person with SCI is examined, and the injury severity is typically classified according to the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) (1, 5). This classification is based on ten key muscles groups for establishing motor level of injury on each side, while the sensory level is determined from a dermatome map (6), with 23 levels on each side (see Figure 1). Finally, neurological level of injury - the most caudal level with maintained function - is determined. Taking the motor and sensory level into account, the extent of the SCI, i.e. the completeness of the lesion, is classified according to the well-established system called the American Spinal Cord Injury Association (ASIA) Impairment Scale (AIS) (1), see table 1.

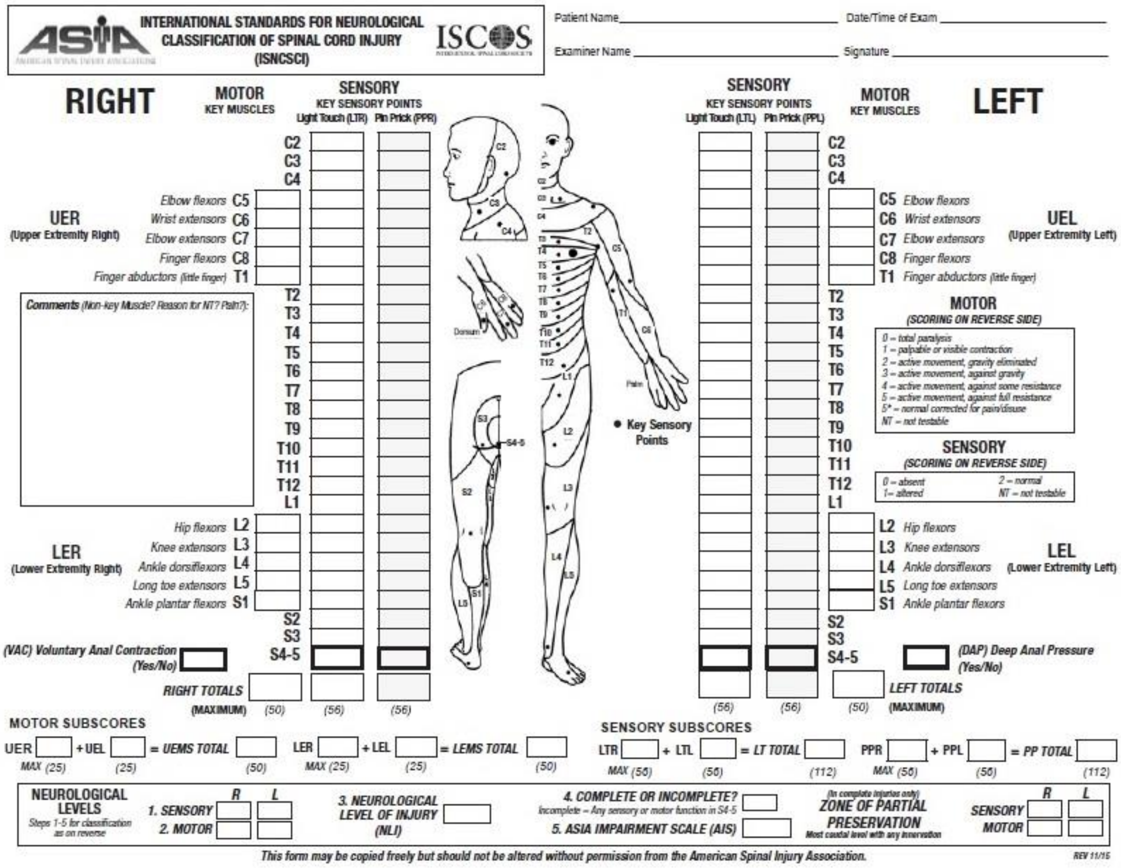

Figure 1. Worksheet according to International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) (1,6).

Table 1. Classification of extent of spinal cord injury according to American Spinal Cord Injury Association (ASIA) Impairment Scale (AIS) (1,5,6).

A Complete Injury	No sensory or motor function is preserved in the sacral segments S4-S5.
B Incomplete	Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5.
C Incomplete	Motor function is preserved below the neurological level, and more than half of the key muscles below the neurological level have a muscle grade less than 3.
D Incomplete	Motor function is preserved below the neurological level, and at least half of key muscles below the neurological level have a muscle grade greater than or equal to 3.
E Normal.	Sensory and motor functions are normal.

Functional outcomes depend on the combination of level and extent of injury, as in the striking illustration by Professor Richard Levi, in figure 2. Persons with AIS A-C usually become wheelchair users, while persons with AIS D injuries usually remain, to some extent, ambulatory (7). The level of functioning may however be reduced by spasticity, impaired sensitivity and muscle weakness, leaving individuals commonly dependent on the use of walking aids. There is also a group of individuals who vary between walking with aids and using a wheelchair, depending on the situation.

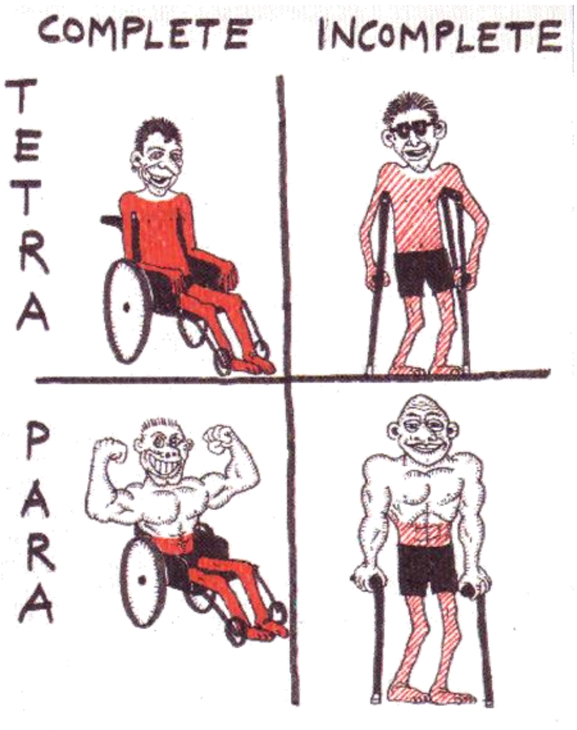

Figure 2. Artistic illustration of the functional outcome depending on level (tetra/para), and extent (complete/incomplete) of SCI. Illustration by Professor Richard Levi from Spinalis Handbook, published with kind permission from Richard Levi and Claes Hultling.

1.2.2 Incidence, etiologi and trends

The incidence and prevalence of SCI around the world vary greatly, with persisting lack of such knowledge in many countries. In North America, Europe and Australia, an incidence between 3.6 and 130.7 per million have been reported in a review (8), while an incidence between 5.9 and 21.2 per million had been recently reported for Nordic countries (2, 4, 9, 10). Concerning the prevalence, in North America it has been reported to be around 721–4187 per million, (11-13) and approximately 681 in Australia (14). Regarding the Nordic countries, 280 per million persons are living with SCI in Finland, while in Iceland, with a population of 250.000 at the year of the study (1983), the SCI population were estimated to consist of 79 persons, equaling to 316 per million (15, 16).

Spinal cord injuries are classified as traumatic or non-traumatic, determined by the following prioritized order outlined by the ISNCSCI: (1) sport and leisure activities, (2) assault, (3) transportation, (4) falls, (5) other traumatic causes, (6) non-traumatic or unknown. In western countries traffic crashes have for a long time been the most common cause of SCI, but in recent decades the proportion of falls (falling, stumbling or jumping) has increased (3, 17, 18). Trauma due to falls or transportation is the most common cause of SCI in the Nordic countries (4, 9, 10, 15, 19), and falls are often the leading cause of SCI for older persons (2, 3, 9, 17). Non-traumatic causes of SCI may be congenital, genetic disorders or acquired abnormalities such as infections or vascular disorders.

From a physiotherapy point of view, many patient problems may be similar regardless of the cause of SCI, i.e. traumatic versus non-traumatic. However, comorbidities and other contextual factors play an important role in the management of the patient. This thesis focuses solely on persons with traumatic SCI.

Historically the proportion of men has been around 80% (10,18), but the proportion of women is slowly increasing over the last period (3, 17). Further, a tendency towards more incomplete injuries has been reported with an incidence of 56-67% (2-4, 18).

There is a trend of an ageing SCI population, due to better medical care and life-long follow-up programs, causing people with SCI to survive fatal injuries and live longer with their injury (17). Also, the age at injury is increasing in the western world. Recent studies show an average age at injury around 37-45 years (3, 9, 17, 19), partly reflecting an overall ageing population. With increasing age at injury the number of pre-existing co-morbidities also increases, as well as the frequency and number of secondary conditions (7) causing new challenges for the system of care. The expected outcome of the rehabilitation when injured at a higher age seem to be a little lower (20, 21) but the impact of age on functioning outputs require further research.

1.2.3 Consequences of SCI

Aside from impact on motor and sensory function in the limbs, a person with SCI also often have problems with bladder and bowel function, spasticity, sexual, autonomic cardiovascular and respiratory dysfunction affecting the person to a various degree depending on the level and extent of the injury (22).

Whilst living with an SCI, there is a high risk of secondary complications such as pressure ulcers, deep vein thrombosis, severe neurogenic pain, bladder problems (23-25).

For wheelchair users, the bone mass density becomes reduced below the level of injury early after the onset of SCI (26), and in chronic stages the lower extremities often become osteoporotic why there is a great risk of fractures if falling (26, 27). Fall-related injuries might lead to increased dependence in daily activities, thus increasing the cost for society as well as the suffering for the individual. Moreover, for a wheelchair user, a fractured leg in a cast might lead to secondary complications such as pressure ulcers due to altered sitting position. Hence, this is a vulnerable group where fall-related injuries may have detrimental effects.

1.2.4 Rehabilitation and lifelong follow-up

Rehabilitation means striving for independence - both physical and psychological, and learning to live with your residual disability in different challenging situations. To manage activities in daily life, getting back to work and cope with family and friends again is hard work. Further, persons with SCI experience more secondary complications than the non-SCI population. Programs for life-long follow-up are therefore designed in order to avoid and/or reduce the impact of secondary conditions/complications which are a threat to health and independence. Such programs often include examination of physical function such as, level of SCI and AIS, spasticity, screening for pressure ulcers, and ordinary blood chemistry. Since numerous prevention programs have been developed, the eventual need for new prevention programs of unwanted secondary complications has to be thoroughly investigated, and the best way of applying them has to be established prior to implementation.

1.3 FALLS AND FALL-RELATED INJURIES

Why measuring falls? Among all the other secondary prevention focuses, falls as such has been brought up as a fairly new field. A fall with no injuries or other negative consequences does not imply a problem. A fall now and then can instead indicate that the person is pushing the edge of his/her functional limits trying to expand his/her independence while regaining, achieving, or maintaining an active lifestyle. On the other hand a fall related injury, or other negative consequences of a fall such as fear or concerns about falling, might instead threaten the achieved level of independence and / or lifestyle. Falls generally result from an interaction of multiple and diverse risk factors, and are often classified as intrinsic (e.g. weakness in lower extremities, reduced balance capacity), extrinsic factors (e.g. polypharmacy) and environmental factors (e.g. poor lightening) (28), and risk-taking behavior may further influence the risk of falling (29). The causes for falls and recurrent falls are likely to be multifactorial and should therefore be investigated within a broad perspective, that takes into account a variety of modes of mobility, diverse age range, and hence potentially different fall risk profiles among persons with SCI.

1.3.1 Definitions

A fall, according to the Prevention of Falls Network Earth (ProFaNe) (30), has been defined as “an unexpected event in which the person come to rest on the ground, floor, or lower level”. Regarding length of reporting periods for falls, a balance exists between possible inconveniences on participants, costs and scientific benefit. In order to include possible seasonal fluctuations in fall frequency, a longer period is preferred, and to enable comparison of fall incidence, a surveillance of falls per person per year has been recommended (31).

In this thesis, the term *associated factors*, is used for any associations found in retrospective or cross-sectional data analysis. *Risk indicators* are used for positive significant associations when temporal association can be determined (i.e. prospective design). Importantly, temporal associations do not imply causality.

1.3.2 Incidence of falls

Many studies on falls in different populations starts with “.. falls are common in the x population”. However the incidence of falls is more or less unknown within the “general population”, hence it is difficult to tell if the risk in a specified group is increased or not. The only study found was Talbot et al (32), who investigated falls among adults from the age of 20 years. The incidence of falls, reported for a two year retrospective period, increased with age from 18% in the young (20-45 years), to 21% in middle-aged (45-65years) and 35% in older adults (>65 years). Further, a few studies conducted with adults used as control groups in studies regarding persons with neurological conditions, have been performed indicating a one year incidence of 15-66% (34-36). Several studies refer to the one study by Tinetti from 1988 by quoting a yearly fall incidence of around 30% in elderly people (33). However, measuring falls in the “general population” is of course difficult and, sometimes also unnecessary if the falls don’t have negative consequences. Prospectively measuring of the incidence of falls requires time and resources; therefore many studies are performed using a retrospective/cross-sectional design or short follow-up. Moreover, prospective studies have different follow-up periods and methods, which may further complicate comparisons.

At the start of the SCIP Falls study in 2012, only a few papers had been published on falls after SCI, with us now experiencing an increasing body of knowledge, especially regarding ambulatory persons. Falls seem to be common in the SCI population, with a high reported incidence of both falls and recurrent falls (37-43). Previous recurrent falls have been shown to increase both the risk for future falls and for related injuries (44-46) in elderly ambulatory persons. Moreover, recurrent falls have been reported to be easier predicted than single falls and as more closely related to neurological and musculoskeletal impairments (46). For wheelchair users, a fall incidence of around 30% during a 12 month prospective follow-up has been reported by Nelson et al (37).

1.3.3 Associated factors and risk indicators for falls

Since the start of the SCIP Falls study potential risk indicators for falls in persons with SCI had only been investigated in a few studies (40, 47, 48). Since then, more studies have been published, although focusing mainly on ambulatory persons (39, 41, 49, 50). The association between different levels of walking ability and balance capacity, and the risk of falling remains uncertain (41, 50, 51). Decreased strength in the lower extremities, loss of balance, and environmental hazards were factors perceived by ambulatory participants themselves as contributing factors to falls (47). Further, in recent studies, mobility level, comorbidity (39) and fear of falling (41) were reported as associated factors in a sample with mostly ambulatory persons.

For wheelchair users with SCI, associated factors and risk indicators for falls have been investigated specifically in one study (37) and in a few with mixed samples (38, 39, 42, 52-56). Paraplegia (53) or higher level of functional independence (53), male sex (53), younger age (53), pain (37), higher alcohol consumption (57), history of previous fall (37), fewer years since SCI (37), and shorter wheelbase of wheelchair (37) have all been shown to be associated with falls. Consequently, this diversity of factors indicates that falls in wheelchair users with SCI is a complicated matter and that consensus on risk indicators of falls in this population is not yet established and calls for further investigation. Notably, the study by Kirby et al (53) used a retrospective design with a long reporting period (time since injury), causing a high risk of recall bias, and included a sample of wheelchair users with different diagnoses with 24% having SCIs.

1.3.4 Fall-related injuries

Concerning fall-related injuries in persons with SCI, knowledge is even more fragmented and limited than for falls itself, and the incidence has been reported ranging from 10-14% per year (37, 42), to 10% during the preceding 6 months (54). For wheelchair users, 47% reported fall-related injuries since onset of their wheelchair use in a retrospective study by Kirby et al (53).

1.4 FALL-RELATED PSYCHOLOGICAL ASPECTS

There are several different fall-related psychological constructs, such as fear of falling, fall-related self-efficacy and balance confidence. In this thesis, the constructs fear of falling and concerns about falling will be used, and fall-related psychological concerns will be used as a generic term. According to Yardley & Smith (58), fall related psychological concerns includes not only the actual concern about falling but also the concern about pain and suffering, fear of losing one's independence and fear of embarrassment when around others. Concerns about falling can be warranted and justified as a protection mechanism, such as to avoid icy and slippery surfaces, but it can also be related to social dysfunction leading to activity restrictions (59).

Fear of falling can be defined as “low perceived self-efficacy at avoiding falls during essential, nonhazardous activities of daily living" (60) or as “a lasting concern about falling that leads to an individual avoiding activities that he/she remains capable of performing” (61). It is often assessed with a single item question “in general, are you afraid of falling? ”(58). This is a user-friendly method with, however, limited responsiveness (58, 62).

Tinetti et al developed the Falls Efficacy Scale (FES) (60) that is heavily underpinned by Banduras social cognitive theories about the cognitive process that lies behind emotions (63). FES was later modified into Falls Efficacy Scale International version (FES-I) (64, 65), which is regarded as measuring concerns about falling (65), although the name might be confusing. The scale addresses concern about falling during 16 daily activities, such as dressing one-self and walking. For each item, concern is rated from 1 to 4, with 1 indicating not at all concerned and 4 very concerned, which, taken together results in a possible score of 16-64 points. FES-I has been used as a gold standard when assessing concerns about falling. The initial validation method has later been criticized but the instrument remains being regarded as an appropriate tool (66). Fear of falling and concerns about falling have been considered as closely related but separate constructs (67), however, there is still a need to further clarify different methods of measuring fall-related psychological concerns (62, 68).

To enable assessment of concerns about falling in wheelchair users, Boswell-Ruys et al developed the SCI Falls Concern Scale (SCI-FCS) based on the FES-I, with 16 items and the same system for grading concerns. It was designed in consultation with SCI professionals (unfortunately not persons with SCI), and assesses concerns about falling during 16 everyday activities that reflect important aspects for an independent life of persons with SCI (possible to perform for a person with SCI level of cervical 7 to thoracic 12). It was tested in a sample of 125 persons with a mean age of 41 years, and mean time since SCI of 9 years. Median score was 24 out of 64 possible, and participants with few previous falls, high level of SCI, those who could not get up from the ground by them-selves and those with poor perceived sitting ability reported higher levels of concern about falling. Pushing wheelchair on uneven surface, up/down gutters or curbs and transferring one-self to a toilet or commode were the activities causing highest concerns. The SCI-FCS showed promising validity, a Cronbachs alpha of 0.92, and factor analysis revealed three underlying dimensions.

The relationship between falls and concerns about falling is ambiguous, and it is further complicated by avoidance of activities with increased risk of falling (58). Falls can cause warranted fear, decreasing the risk of falls which is positive, while unwarranted fear have been shown to cause avoidance and lower quality of life in elderly persons (58). Fear of falling has also been shown to contribute to increased risk of falls (69). Attempts have been made to reduce fear of falling with exercise, but effective treatment remains difficult (70).

1.5 FALL RISK ASSESSMENTS

Can falls be predicted? Falls are by nature complex matters which can be explained by internal and external causes and/or hazards in the environment. Screening for falls is often performed in the everyday clinical work in order to avoid falls and fall-related injuries. Screening can be done by staff judgement (71, 72) and/or screening instruments such as Downton Fall Risk Index (73, 74) and Stratify (75) as commonly used in the Nordic countries. Wheelchair use is regarded as a protective factor for falls compared to unsafe ambulation and equal to safe ambulation according to Downton Fall Risk Index, while according to Stratify the overall risk is regarded as lower than ambulation (73, 75). Since falls seem to be common after SCI, it is essential to use fall risk screening instruments evaluated for this group, and since none was found at the time, it remained important to validate the existing instruments for wheelchair users with SCI.

1.6 MEASUREMENTS AND VALIDITY

Valid and reliable measurements are necessary in order to enable assessments of clinical work as well as scientific studies. Where reliability concerns the robustness of the instrument when assessed at different occasions, or by different administrators, validity concerns whether or not the instrument reflects the construct (or phenomenon) that it is supposed to measure. Within this thesis, focus will be on validity. For an instrument to be valid, it has to be translated and adapted according to guidelines for use in other cultural contexts as well as adapted and tested for the selected population (76, 77).

The COSMIN group (Consensus-based standards for the selection of health measurement instruments) has recommended a model for validity and reliability (78) when assessing quality of health-related self-reported measurement instruments. *Validity* was defined as the degree to which an instrument measures the construct(s) it purports to measure. *Criterion validity*, defined as the degree to which the scores of an instrument adequately reflect an existing gold standard, can be examined by means of concurrent and predictive validity. *Concurrent validity* is performed by examining a new instrument with the gold standard at the same time, whereas predictive validity assesses how well the new instrument can predict the gold standard. If a "gold standard" does not exist in the examined field, content and construct validity should be assessed. *Content validity* is the degree to which the content of an instrument correctly agree with the construct to be measured. The latter subsumes face validity, the degree to which the items of the instrument seems to correctly agree with construct to be measured. Finally, *construct validity* defined as the degree to which the scores of the instrument correctly agree with the hypothesis about the construct, can be assessed. Construct validity can be divided in to structural validity, hypothesis testing and cross-cultural validation (regarding translated instruments).

In this thesis, tested instruments (mainly content and construct validity and reliability) have been used when eligible, but some instruments were not yet validated for persons with SCI and we therefore had to rely upon instruments tested in other populations.

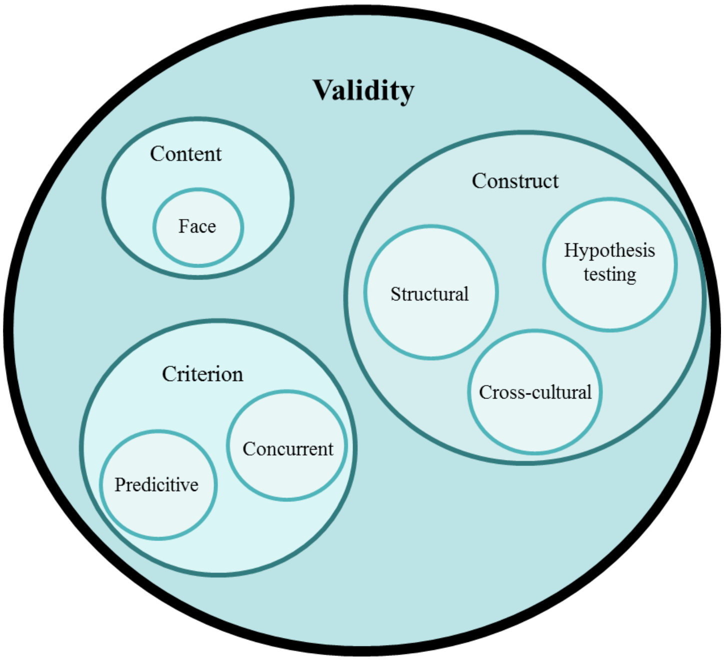

Figure 3. Validity according to COSMIN (COnsensus-based Standards for the selection of health Measurement Instruments) taxonomy of measurement properties. The displayed figure is part of a larger model.

1.7 THESIS RATIONALE

Since the research area of falls after SCI has recently become a growing field of interest, few prospective studies have been carried out, especially concerning wheelchair users. It is indicated that falls are common after SCI, but basic knowledge is still limited. Moreover, due to the low number of studies with different designs and samples, consensus regarding risk indicators for falls and fall-related injuries has still not been reached. The wide age span, as well as different modes of mobility, further complicates the task. In addition, persons with SCI, especially wheelchair users, are exposed to many secondary complications throughout their life-time and falls and related injuries might further impair their situation.

Identification of individuals with a high risk of falls and fall-related injuries, such as individuals falling repeatedly, is therefore an important part of the health care agenda. This may lead to better preventive interventions, and thus fewer falls and fall-related injuries, which, in turn, possibly increases quality of life of the individuals as well as reducing costs for society. To enable effective screening for risk of falls, measurement instruments have to be tested for this specific group. So far, there are no published studies regarding fall risk instruments for persons with SCI. Further, there is a risk that falls or experienced risk of falls, might lead to concerns about falling which might negatively impact activity and participation of persons with SCI. How concerns about falling possibly affect wheelchair users with SCI remains unknown, and evaluated instruments are required to enable further clarification. Consequently, it is important to fill the gap of knowledge about falls, fall-related injuries, concerns about falling and screening for falls in persons with SCI, especially the wheelchair users. Basic knowledge regarding incidence and associated factors are necessary in order to enable the development of future programs for screening and prevention of falls and fall-related injuries in persons with SCI.

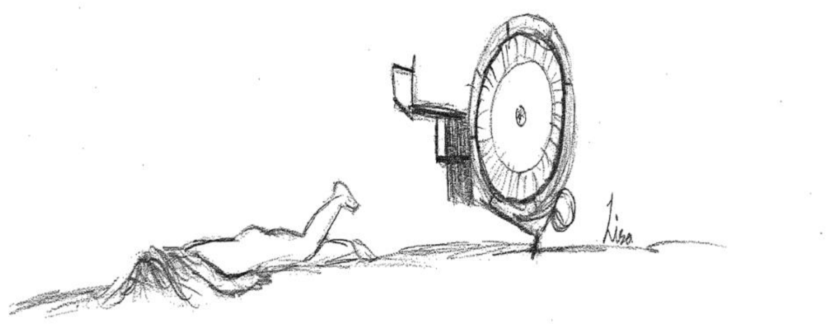

Illustration by Lisa Forslund

2 AIM

The overall aim of this thesis was to broaden the base of knowledge regarding falls and fall related injuries after chronic traumatic SCI, particularly concerning the incidence and risk indicators for recurrent falls with a predominant focus on wheelchair users. Further, to investigate the validity of measurement instruments capturing concerns about falling and fall risk prediction. The specific aims of the included papers in this thesis were as follow.

Paper 1: to translate and cross-culturally adapt the SCI-FCS to Swedish, and to evaluate its psychometric properties including construct validity and internal consistency, and to assess its structural validity.

Paper 2: to identify factors associated with recurrent falls in individuals with SCI (including both ambulatory persons and wheelchair users).

Paper 3: to identify the incidence of falls and recurrent falls, describe the circumstances around the falls, and the risk indicators for recurrent falls. The aim was further to identify the incidence and severity of fall-related injuries, and to describe risk indicators for fall-related injuries in wheelchair users with SCI.

Paper 4: to investigate the predictive accuracy of the Downton fall risk index and the single item question of falls the previous year in community-dwelling wheelchair users with SCI.

3 METHODS

This thesis consists of four papers: a retrospective and a prospective paper, respectively, on falls after SCI and two papers on the validation of instruments for assessing concerns about falling and fall risk. See table 2 for an overview of paper 1-4.

Table 2. Overview of papers.

	Type of study	**Participants n**	**Main outcome**	**Data collection methods**
Paper 1	Validation study	87 Swedish wheelchair users	Validation of the Swedish version of SCI-FCS	Translation, adaptation, validation
Paper 2	Retrospective cohort study	224 (151 wheelchair users, 73 ambulatory)	Factors associated with retrospective recurrent falls	Interview, clinical assessments, self-reported questionnaires
Paper 3	Prospective cohort study	151 wheelchair users	Incidence and risk indicators of recurrent falls and related injuries	As paper 2 + fall registration by sms, telephone interview
Paper 4	Validation study	151 wheelchair users	Predictive accuracy of Downton Fall Risk Index, and previous falls	As paper 2 + fall registration by sms

3.1 SETTINGS

The study was executed in two centers delivering specialized neurological rehabilitation, with specific assignments of providing SCI rehabilitation and life-long follow-up. Rehab Station Stockholm/Spinalis (Rehab Station/Spinalis) is one of Sweden's largest centers for neurologic rehabilitation. It is situated in Solna just outside Stockholm with a catchment area of Greater Stockholm with around 2.3 million inhabitants. Multiprofessional teams, with the addition of a unique emphasis on peer learning, facilitate the rehabilitation process. Sunnaas Rehabilitation Hospital (Sunnaas RH), at Nesodden outside Oslo in Norway is one of the largest rehabilitation hospitals in Europe. Sunnaas RH is in charge of rehabilitation and life-long follow-up of persons with SCI in Helse SørØst (the south-east part of Norway) with a catchment area that includes around 2.8 million inhabitants.

3.2 PARTICIPANTS

Of the 270 eligible persons who were scheduled for annual check-ups, 224 were consecutively recruited whilst attending to their regular visits to the programs of life-long SCI follow-up at Rehab Station/Spinalis, and Sunnaas RH. The inclusion of participants was carried out between February 2013 and April 2014, with 118 Swedes and 106 Norwegians recruited. For further information, please see flowchart, figure 4.

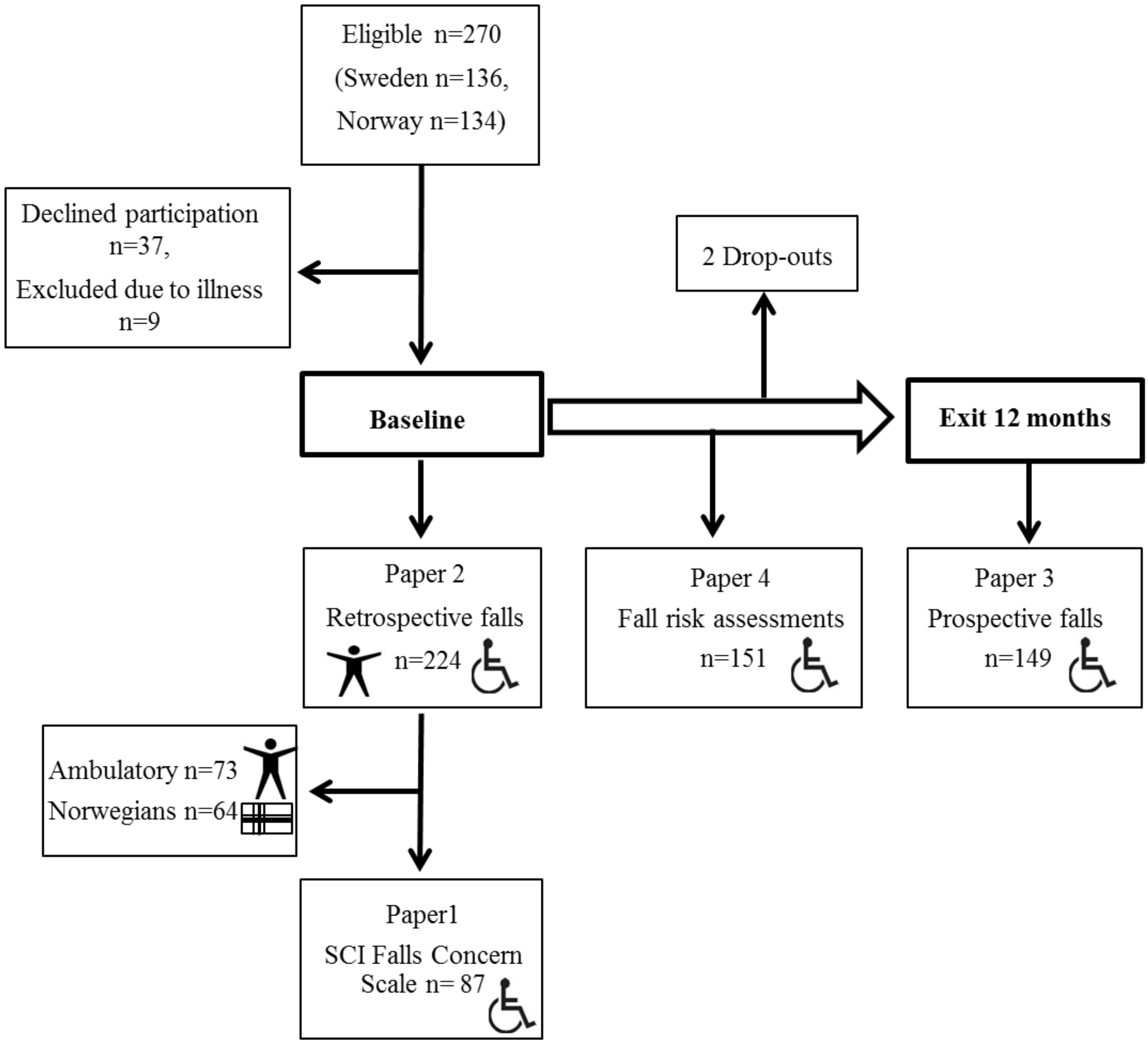

Figure 4. Flowchart of number and mode of mobility of participants across the four papers; including reasons for exclusion and number of drop-outs at follow-up.

The overall inclusion criteria were: persons with traumatic SCI, at least one year post injury, ≥ 18 years of age and able to cooperate and understand spoken and written Norwegian or Swedish. Exclusion criteria were: motor complete injuries above C5 level (American Spinal Cord Injury Impairment Scale [AIS] A and B), injuries below L5 level and injuries classified as AIS E (normal sensory and motor functions) according to International Standard Neurological Classification of Spinal Cord Injury (1). For further details, see flowchart.

Additional criteria's for the different papers.

Paper 1, those using wheelchairs for at least 75% of their mobility needs (79), from the Swedish sample.

Paper 3, using wheelchair for at least 75% of their mobility needs.

Paper 4, using wheelchair for at least 75% of their mobility needs.

3.3 DATA COLLECTION

Baseline data were collected by the use of interviews, clinical tests and self-reported questionnaires (see table 3 for details), while short message service (sms) (paper 1-4), and telephone interviews were used for data collection at the follow-up phase (paper 3 and 4). To certify the quality of data, all data gathering was performed in the same order by the author (EBF) in the Swedish setting and by Vivien Jørgensen (VJ) in the Norwegian setting, both with more than 15 years' of experience in SCI rehabilitation. Pilot studies and inter-rater training were performed prior to the start of data collection.

3.4 OUTCOME MEASURES

The main outcome measures at baseline data collection and follow-up are presented below, for further details please see included papers and table 3. The prospective registration of falls only comprises the wheelchair users in this thesis. The results of the ambulatory persons are reported in the thesis by Vivien Jørgensen, Karolinska Institutet 2016 (80), and in the paper by Jørgensen et al (81).

3.4.1 Baseline data collection of SCI characteristics and physical function

The two investigators (EBF, VJ), assessed and classified all participants together with an experienced physician at each site, according to the guidelines of the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) (1,5), as presented in the background.

Mode of mobility: Self-reported use of wheelchair/ambulation for mobility needs was categorized with inspiration from Boswell Ruys et al (79) as: 100% wheelchair user, 75% wheelchair + 25% ambulatory, 50:50, 25% wheelchair + 75% ambulatory, or 100% ambulatory. Those reporting at least 75% of wheelchair use were classified as wheelchair users in this thesis.

SCI classification: Level and extent of SCI were classified according to the International Standards for Neurological classification of SCI (1). Please see background for further information.

Functional independence: functional independence was assessed with the mobility subscale of the Spinal Cord independence Measure (SCIM) version III. The mobility subscale comprises nine items including transfers between wheelchair and bed / toilet / bath, and ability to negotiate stairs. The activities were self-reported by face-to-face interview, and the sum score was calculated, with a possible score of 0-40. The instrument had been developed and tested for persons with SCI (82-84).

Ability to get-up: This ability was assessed with a single item question; "if you fall, are you able to get up by yourself without the use of additional aids or help? " The possible answer was a simple no or yes. A similar question was used in the SCI-FCS (79).

Level of exercise: Physical activity was defined as any bodily movement that increases energy consumption beyond the resting metabolic rate (85). Exercise was defined as planned, structured, and repetitive physical activity aiming to maintain or improve physical fitness such as muscle strength and or aerobe capacity (85). The level of exercise was assessed as self-reported exercise habits the previous year in accordance with the Public Health Agency of Sweden (86). There were four possible answers: 1, exercise ≥30 minute three or more times a week, 2, exercise ≥30 minute once or twice a week, 3, physical activity ≥ two hours a week or 4, physical activity less than two hours a week. The categories were dichotomized as performing regular exercise (category 1-2) or not (category 3-4).

3.4.2 Baseline data collection of falls and risk of falls

Participants were asked about the number of falls and fall-related injuries the year prior to inclusion. Falls during follow-up that were directly related to sports were not considered as unexpected events, and were therefore registered but excluded from further analysis (87, 88).

Since falls seem to be frequent in the SCI population, and repeated falls may be a risk factor for future and injurious falls (46) (44, 45) recurrent falls was chosen as the main outcome measure. The definition of recurrent falls set at >2 falls (89) was chosen since a follow-up period of 1 year was preferred, in order to account for possible seasonal variations in frequency of falls. Falls in the previous year was assessed during the structured interview by use of a single item question. A semi-structured scheme and follow-up questions were used to reduce recall bias (i.e." Have you fallen the previous year?", if yes ,"How many times did you fall? How many times per month/week?")

Risk of falling: Downton Fall Risk Index (74) was used for the assessment of risk of falling. The instrument was developed for elderly persons, and has been validated for use in Swedish settings among elderly and persons with stroke (73, 90). The sum score was calculated (0-11), and participants were then allocated to either a low or high risk group, with a sum score ≥3 regarded as high risk of falls according to previous studies (73, 90). Visual impairment was registered if a participant "with or without glasses, was not able to read a word in 5mm block letters at reading distance", and hearing impairment was registered if the participant "without hearing aid was not able to perceive a conversation in a normal voice at a distance of 1m" (73). Further, limb impairment was registered for all participants due to the inclusion criteria of wheelchair use. All participants had to be capable of cooperating during the testing procedure. Moreover, they had to manage the design of the study with telephone follow-up after falls. All participants were considered as mentally oriented. Medication was registered by use of a structured interview. Walking ability was defined as safe, according to the description by Rosendahl et al (73), if the participant without walking aids was able to "move easily and safely when, for example opening and closing doors, meeting people in the hallway, and approaching a chair to sit down".

3.4.3 Baseline data collection of fall-related psychological concerns

Concerns about falling with more detailed information in the background section, were assessed at baseline with the SCI-FCS for wheelchair users and FES-I for ambulatory persons. Both scales are self-reported questionnaires, where concerns about falling are assessed in relation to specific activities. The FES-I consists of 16 activities, including, but not limited to, getting dressed, preparing meals and walking in different environments. Concerns about falling are assessed for each item as; not at all concerned (1 point), somewhat (2 points), fairly (3 points) or very concerned (4 points), with a sum score ranging between 16-64. The FES-I was developed for elderly persons (65), and the Swedish version has shown promising validity (91). However, no validation of the instrument for the SCI population has been published yet, but it has been used in one study on ambulatory persons (92).

The SCI-FCS (79) consists of 16 items covering activities such as getting dressed, transferring between wheelchair and bed, and pushing one's wheelchair in different environments. Grading and calculation of the sum score are performed according to the FES-I. The SCI-FCS has been translated to Norwegian, and showing good reliability (93), and the translated Swedish version (see paper 1) was used in this thesis.

Fear of falling was assessed with a single item question: in general, are you afraid of falling? (58, 60). The possible alternatives were: not at all, a little afraid, quite a bit afraid, and very afraid. In paper 2, the alternatives were dichotomized as: not at all/a little afraid compared to quite a bit afraid/very afraid. In order to compare the results to others (41) in paper 3, the dichotomization was not at all compared to a little/quite a bit/very afraid.

3.4.4 Baseline data collection of quality of life and psychological aspects

Quality of life: general quality of life was assessed with the question from the ISCoS quality of life basic data set (94, 95). It is a scale ranging from 0 to 10 with those closer to 0 indicating more dissatisfaction whereas scores closer to 10 indicates high levels of satisfaction. This question was assessed using interviews where the participants graded their overall satisfaction with quality of life.

Symptoms of anxiety and depression: the self-reported questionnaire Hospital Anxiety and Depression Scale (HADS) was used to assess how subjects felt during the last week. The instrument consists of 14 items with possibilities of calculating the sum score for both anxiety and depression subscales, respectively. A subscale sum score of more than seven was used as an indication of depression or anxiety. The instrument has previously been used in Nordic settings (96-98) and among persons with SCI (99, 100).

3.4.5 Baseline data collection of fatigue

Fatigue: Fatigue was assessed with the Fatigue Severity Scale (FSS) (101), assessing the influence of fatigue on function. It consists of 9 statements, where the person indicate the agreement to the statements, from strongly disagree (1) to strongly agree (7).

The sum score is calculated with a mean score above 4 indicating fatigue. The latter was however revised, and currently a mean above 5 has been recommended (102). In paper 1, unfortunately a typing error has been detected. According to the text a mean score of more than 4 was used, while instead a mean score of more than 5 was used, as in the cited reference. The FSS has been used in SCI samples (103) and showed acceptable reliability and validity

Table 3. Overview of primary and secondary outcome measures, instruments and units in the four papers.

Outcome	Instrument (reference)	Unit	Paper 1	Paper 2	Paper 3	Paper 4
PRIMARY						
History of falls	Falls previous year	Number, categorized as 0-2/>2	•	•	•	•
Registered falls	Falls during 1 yr follow-up	Number, categorized as 0-2/>2			•	•
Fall with injury	Fall-related injury previous year	Number	•	•	•	
	Fall-related injury during 1 yr follow-up	Number, categories			•	
Risk of falling	Downton Fall Risk Index[74]	Number, categorized as 0-2/>2		•	•	•
SECONDARY						
Personal factors						
Sociodemographic	Age	Years	•	•	•	•
	Sex		•	•	•	•
	Education-level	Classification, 3 levels		•	•	
	Working or studying	No/yes	•	•	•	
Alcohol consumption	Consumption per month World Health Organization	4 (women) or 5 (men) units at once at least once per month		•	•	
Risk willingness	One question: "I like to take chances."[104]	No/yes		•	•	
Fall-related psychological concerns	SCI Falls Concern Scale[a,79,93]	Sum score 16-64	•	•	•	
	Falls Efficacy Scale-International[b, 65,91]	Sum score 16-64, dichotomized as 16-22/23-64		•		
	Fear of falling[58,60]	Classification 4 levels, dichotomized as 1-2/3-4	•	•	•	
Body function & structure						
Body mass	Body mass index			•	•	
SCI characteristics	Duration of SCI	Years	•	•	•	
	Injury etiology (ISNCSCI)[1,5,6]	Classification 5 categories		•	•	
	Injury level (ISNCSCI) [1,5,6]	Dichotomized as C1-8/T1 -L5	•	•	•	
	AIS score[1,5,6]	Classification A-D	•	•	•	
Sensibility	Light touch (ISNCSCI) [1,5,6]	Sum score 0-100		•	•	
Pain	Pain items from SCI Secondary Conditions Scale[105]	Classification 4 levels, dichotomized as low: 0-1/high: 2-3	•	•	•	
Spasticity	Spasm item from SCI Secondary Conditions Scale[105]	Classification 4 levels, dichotomized as low: 0-1/high: 2-3	•	•	•	
	Spasm frequency[106,107]	Classification 4 levels		•	•	

	Spasm severity[106,107]	Classification 3 levels		•	•	
	Modified Ashworth Scale[106]	Classification 5 levels		•	•	
Muscle strength	Motor score, upper and lower limb (ISNCSCI)	Sum scores 0-50		•	•	
	Timed Stands Test[b,108]	Seconds		•		
Fractures	Fracture after SCI	No/yes		•	•	
Fatigue	Fatigue Severity Scale[101-103]	Average score, dichotomized as 0-4/≥5	•	•	•	
Depression and anxiety	Hospital Depression and Anxiety Scale, 2 subscales[96-100]	Sum scores 0-22, dichotomized as 0-10/≥11	•	•	•	•
Secondary conditions	Secondary conditions scale[105]	Sum score dichotomized as 0-10/≥11	•	•	•	
Activity and participation					•	
Functional status	Mode of mobility[79]	Dichotomized as at least 75% wheelchair user/ambulatory		•	•	•
	SCI Independence Measure, version III, mobility items[82,84]	Sum score 0-40	•	•	•	•
	Able to get up by oneself[c]	No/yes	•	•	•	
Wheelchair skills	Timed 200 m wheelchair pushing[a, 109]	Seconds (30-m including turns)	•	•	•	
	Ascend 10 cm ramp unaided[a]	No/yes	•	•	•	
Walking skills	10-m Walk Test[b, 110]	Seconds, preferred walking speed		•		
	Timed Up and Go[b, 111]	Seconds, preferred walking speed		•		
Balance	Berg Balance Scale[b, 92]	Sum score 0-56		•		
	T-shirt test[a, 112]	Seconds	•	•	•	
Physical activity	Level of exercise previous year[86]	Classification; 4 levels, dichotomized as regular exercise no/yes	•	•	•	
	No. of sitting transfers per day[a]	Dichotomized as 0-14/≥15	•	•	•	
Quality of life	ISCoS basic dataset; general quality of life[94-95]	Rating 0-10	•	•	•	•
	Euroqol 5 Dimensions 5 levels, self-perceived health today[113]	Rating 0-100%	•	•	•	
Environmental factors						
Aids	Walking aids[b]	Classification: none/crutch or cane/walker		•		
	Walking Index for SCI, version II[114]	Classification levels 0-20		•		

Abbreviations: FSS, Fatigue Severity Scale; HADS, Hospital Anxiety and Depression Scale; ISCoS, International Spinal Cord Society; ISNCSCI, International Standards for Neurological Classification of Spinal Cord Injury; SCI Spinal Cord Injury

[a] Wheelchair user, [b]Ambulatory, [c] Able to get up from the ground by oneself without help from another person and without any other aids than used at the time of fall.

Subscribed numbers refers to list of references.

3.4.6 Follow-up: Registration of prospective falls and fall-related injuries (paper 3-4)

At baseline, participants were presented the definition of falls by ProFaNe and in order to avoid under-reporting they were instructed to report every fall, even if they were not certain if it was considered a fall. Every second week, for a one year period, they received an automatic short message service (sms) asking “Have you fallen the previous two weeks? Please answer yes or no”, see figure 5. If no answer was registered, a reminder was sent out after two days; and if the participant failed to respond to the reminder, they were contacted by telephone. When a fall was reported by sms, a semi-structured telephone interview took place to elicit the circumstances around the fall, number of falls and eventual subsequent fall-related injuries. In addition, regular telephone interviews were performed at 4, 8 and 12 months after inclusion. This was primarily done to confirm that the participants remembered the definitions of falls and to increase compliance. The ©SMS-Track ApS, Esbjerg, Denmark system was used for delivery of text-messages.

Fall-related injuries were defined as no injury, minor, moderate, or severe according to Schwenk et al (115):

- no injury: no physical injury detected.
- minor: minor bruises or abrasions not requiring a medical/health professional assistance; reduced physical function for at least three days or no injury.
- moderate: woundes, bruises, sprains, cuts requiring a medical/health professional examination, such as physical examination, x-ray or sutures.
- severe: medically recorded fractures, head or internal injuries requiring emergency or inpatient treatment.

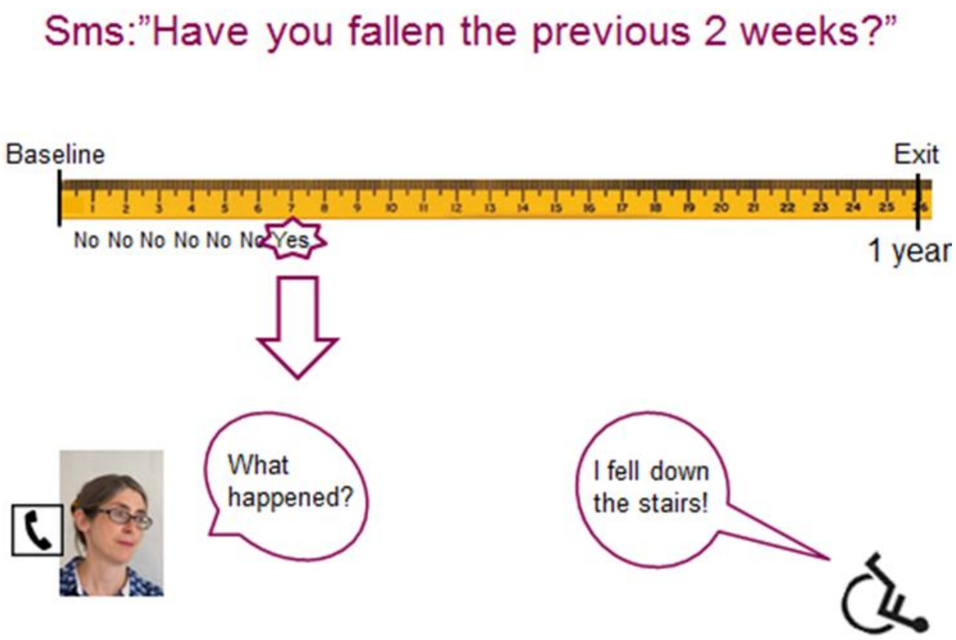

Figure 5. Illustration of the process for registration and follow-up of falls. Falls were registered by sms every second week for one year, and a telephone interview was performed when a fall was reported.

3.5 SAMPLE SIZE AND POWER

In study 2 and 3, the inclusion was based on a rough estimation of approximately 50% wheelchair users with a fall incidence of 30% (37), and 50% ambulatory persons with a fall incidence of around 70% (40). Thus, in order for around 100 persons to fall, 200 participants were required. According to the rule of thumb of allowing 10 cases per variable, contingent upon the selected ten variables for use in the in the logistic regression model (116). A sample of 100 participants per site was equivalent to approximately 12-15% of the respective SCI database at the two units.

3.6 DATA ANALYSIS

Descriptive data are displayed as numbers and percentage, median and interquartile range (IQR), min-max numbers for ordinal and not normally distributed data, and means with SD for normally distributed data. Non-parametric statistics were used for not normally distributed continuous variables. To detect differences between groups student t-test was used for normally distributed continuous data, Mann-Whitney U-test for not normally distributed continuous and for ordinal data, and Chi2 ($\chi 2$) was used for nominal data. Fisher exact test was used for analyzing differences between groups with fewer persons (<5).

All statistical analyses were performed using IBM-SPSS Statistics, versions 22.0 (SPSS Inc., Armonk, NY, USA IBM Corp), and MedCalc Statistical software (MedCalc Software bvba, Acacialaan 22, 8400 Ostend, Belgium https://www.medcalc.org, accessed in October 2016). For an overview of statistical methods in paper 1-4, please see Table 4.

Table 4. Overview of statistics methods

	Paper 1	**Paper 2**	**Paper 3**	**Paper 4**	**Thesis**
Descriptive statistics					
Counts	●	●	●	●	●
Percentage (%)	●	●	●	●	●
Mean (with SD)		●	●	●	●
Median (with IQR, min-max)	●	●	●	●	●
Inferential statistics					
Chi2		●	●		
Mann-Whitney U test	●	●	●		
Students T-test		●	●		
Fisher exact test		●	●		
Specificity/sensitivity				●	
Factor analysis	●				
Rasch analysis	●				
Logistic regression analysis		●	●		
Odds ratios (OR) with 95% confidence intervals (CI)		●	●		
Hazard ratios (HR) with 95% confidence intervals (CI)				●	●
Cox survival analysis				●	●
Kaplan Meier				●	●

SD standard deviation, IQR interquartile range

3.6.1 Paper 1

The SCI-FCS was translated by an expert group of researchers and clinicians, back-translated by two independent and naïve translators with English as their mother tongue, and culturally adapted as recommended (76, 77). First, construct validity was assessed by comparing level of concerns about falling between different groups of participants with different characteristics, for example men and women, and older or younger. Second, a factor analysis was used to explore whether the underlying dimensions of concerns about falling were equivalent in the Swedish and English versions of the SCI-FCS. To determine the number of factors with an eigenvalue >1, principal component analysis with varimax rotation was performed. The scree plot was inspected in order to confirm the number of factors. Third, Rasch analysis was performed according to the item response theory to explore the questionnaire structure, unidimensionality, and to determine the goodness-of-fit for items and persons. Also, Andrich thresholds for the scale-steps were analyzed (117). Finally, Cronbachs alpha was calculated to assess internal validity.

3.6.2 Paper 2 and 3

The number of reported falls was regarded as the dependent variable in the study, which was dichotomized as 0-2 (low frequent) or >2 (recurrent) (89, 118). Further, fall-related injuries were regarded as a dependent variable, dichotomized as no injury versus any injury.

Bivariate regression analysis was performed followed by multivariate regression models with backwards enter mode. The final multivariate model was determined with all variables significant at $p<0.05$. Odds ratios (OR) and 95% confidence intervals (CI) were calculated for factors associated with recurrent falls. Hosmer and Lemeshow tests of goodness-of-fit statistics were used to examine model fit for the final model. Independent variables used in paper 2 were selected based on previous research (37), and in paper 3, the results of paper 2 were considered and used.

Mode of mobility turned out as a significant factor with the highest OR in the paper on retrospective falls when using the total sample (paper 2), therefore the prospective part of the study (paper 3) was performed separately on wheelchair users and the ambulatory subgroups. The results of the ambulatory sample were presented by Vivien Jørgensen in her thesis (80), and in a separate paper (80, 81).

3.6.3 Paper 4

Sensitivity, specificity, negative and positive predictive values and Prognostic Separation Index were calculated and hazard ratios (HR) with corresponding 95% CI were calculated for factors associated with time to first fall. Cox survival analysis was performed on variables from Downton Fall Risk Index including falls the previous year, and significant variables from paper 3 were selected for analysis. Kaplan Meier with Log rank Mantel Cox test for significance was performed to investigate differences in time to first fall between groups with low and high risk of falls according to the Downton Fall Risk Index, and for those who did or did not fall the previous year.

3.6.4 Missing data

Data can be missing legitimately, such as missing response for one person on a specific item of a questionnaire (participant non-response) or a missing response from a certain individual due to withdrawal etcetera (unit non-response). Missing data on self-reported questionnaires (SCI-FCS, FSS and HADS) were replaced by the individual mean value if ≤ 2 items were missing, and in instances where more than 2 items were missing, the sum score was not calculated as recommended by ProFaNe. Other missing data were not imputed.

3.7 ETHICS

The project was approved by the Regional Ethical Review Board in Stockholm County in May 2012 ((Dnr:2012/830-31/2, 2013/391-32, 2014/364-32) and Regional Ethics Committee for Medical Research Ethics (REK) in South-East Norway (Dnr: 2012/531D). All participants provided their written informed consent after receiving oral and written information.

Ethical considerations concerned the long and thorough follow-up which might be experienced as interfering with their privacy. There is also a risk that they felt pressure to participate and complete the study. Further, there was a risk of falling and getting exhausted during the baseline data collection. During the gathering of data, two physiotherapists (EBF and VJ) worked exclusively with SCIP Falls study, and did not engage in the regular work at the SCI units, thus reducing the possible effects of a staff-patient relationship. In spite of the observational character of the study, the investigators answered questions regarding fall-related injuries after the falls during the telephone interviews. Questions regarding physiotherapy or other medical issues were handled by recommending participants to contact their SCI unit.

4 FINDINGS /RESULTS

In this section a summary of the main results from the four papers will be presented together with some additional findings. For more details please see the publications and manuscript.

4.1 PARTICIPANTS

An overview of participant characteristics, of those enrolled in paper 1-4, is presented in table 5 and 6. Of 270 eligible persons scheduled for annual check-ups, 37 denied participation and 9 were excluded due to illness. Nineteen persons classified themselves as combining ambulation and using a wheelchair. Of these, five reported an equal distribution of wheelchair use and ambulation (50:50), and were classified as ambulatory after discussions were held in the research group. Consequently, 224 participants were recruited; of which 151 were classified as wheelchair users and 73 as ambulatory. Two participants withdrew from the study after 4.5 and 8 months, respectively, because they did not want to continue the sms follow-up. As a result, 151 persons were included in papers 2 and 4 and 149 in paper 3.

Table 5. Distribution of participants' spinal cord injury level and AIS classification in paper 2 and 3.

	AIS [1]				
Level [2]	**A**	**B**	**C**	**D**	Sum
Paper 2 n=224					
Cervical	34	17	14	49	114
Thoracic 1-6	26	6	1	0	33
Thoracic 7-12	35	4	3	17	59
Lumbar	5	4	2	7	18
Sum	100	31	20	73	224
Paper 3 n=151					
Cervical	34	17	14	6	71
Thoracic 1-6	25	6	1	0	32
Thoracic 7-12	34	4	1	1	40
Lumbar	5	3	0	0	8
Sum	98	30	16	7	151

[1] ASIA (American Spinal Cord Injury Association) Impairment Scale
[2] refers to neurological level of spinal cord injury

Table 6. Overview of participant characteristics.

	Paper 1	Paper 2	Paper 3	Paper 4
Characteristics	n=87	n=224	n=149	n=151
Gender, n (%)				
Male	65 (75)	173 (77)	123 (83)	124 (82)
Female	22 (25)	51 (23)	26 (17)	27 (18)
Age				
Mean years (SD)	49 (14)	50 (15)	47 (14)	47 (14)
Min-max	18-79	18-83	18-79	18-79
Married/living with partner n (%)				
No	38 (44)	104 (46)	68 (46)	70 (46)
Yes	49 (56)	120 (54)	81 (54)	81 (54)
Education, n[1] (%)				
Secondary school or less	28 (33)	73 (33)	45 (30)	47 (31)
High school	22 (25)	66 (30)	46 (31)	46 (31)
College/university	36 (42)	83 (37)	57 (38)	57 (38)
Working/studying n (%)				
No	40 (46)	123 (55)	75 (50)	77 (51)
Yes	48 (54)	101 (45)	74 (50)	74 (49)
SCI characteristics				
Duration of injury				
Median (IQR)	15 (13)	15 (19)	16 (20)	16 (20)
Min-max	2-52	(1-56)	1-56	1-56
Injury level, n (%)				
Cervical	45 (52)	114 (51)	71 (47)	71 (47)
Thoracic 1-6	17 (19)	33 (15)	32 (22)	32 (21)
Thoracic 7-12	20 (23)	59 (26)	39 (27)	40 (26)
Lumbar	5 (6)	18 (8)	8 (5)	8 (5)
Completeness n (%)				
AIS[2] A	53 (61)	100 (45)	96 (64)	98 (65)
AIS B	19 (22)	31 (14)	30 (20)	30 (20)
AIS C	9 (10)	20 (9)	16 (10)	16 (11)
AIS D	6 (7)	73 (32)	7 (5)	7 (5)
Injury mechanism n (%)				
Sport	22 (25)	51 (23)	37 (25)	37 (25)
Violence	1 (1)	3 (1)	2 (1)	2 (1)
Traffic	36(41)	91 (41)	67 (45)	68 (45)
Fall	25 (29)	69 (31)	37 (25)	38 (25)
Other	3 (4)	10 (4)	6 (4)	6 (4)

[1]Missing data on education for one person
[2]AIS =American Spinal Injury Association Impairment Scale.

4.2 CONCERNS ABOUT FALLING (PAPER 1)

Participants generally reported low levels of concerns about falling with a median SCI-FCS sum score of 21, of possible16-64 points. One participant scored the maximum (64/64), while thirteen (16%) scored the lowest possible (16/64). Those who reported higher SCI-FCS scores also reported symptoms of anxiety, depression and fatigue, had been injured for a shorter time, reported fear of falling, and were not able to get up from the ground independently. Falls with or without injury the previous year, sex, age, sitting balance and level of injury did not influence the level of SCI-FCS score. Internal consistency of the instrument, measured with Cronbachs alpha was 0.95.

The factor analysis revealed three underlying dimensions, similar but not identical to the original version. The first was characterized by different transfer situations and explained 31% of the variance. The second was characterized by different situations when the participants were reaching for or handling objects, but also pushing their wheelchair on even surface, which together, explained further 28% of variance. Finally, the third comprised pushing wheelchair in difficult situations, such as slopes and curbs, which explained a further 15% of the variance.

The Rasch analysis showed an explained variance of 57% (35% by persons, 22% by items). Items 12 (pushing wheelchair on uneven surface) was the only item that did not show goodness of fit. Most items were assembled in the middle of the item-person map, except for item 12 (pushing wheelchair on uneven surface) and 13 (pushing wheelchair up/down gutters or curbs) associated with greatest concerns about falling, and item 11 associated with least concerns (pushing wheelchair on even surface).

4.3 INCIDENCE OF FALLS (PAPERS 2 AND 3)

With the retrospective reporting of falls in the total sample, (paper 2), 76% reported falling during the previous year, and 51% reported recurrent (>2) falls (median 2; min-max 0-500). Among the wheelchair users, 73% reported falling and 41% reported recurrent falls (median 2; min-max 0-500: for distribution of falls in wheelchair users please see figure 6). The person who reported 500 falls (fell at least once per day, often twice) suffered from a severe complication and dramatically reduced the activity level and fell less during the follow-up surveillance period.

When falls were prospectively reported by wheelchair users (paper 3), 96 (64%) reported falling and 45 (32%) reported recurrent (> 2) falls (see figure 6). This was lower compared to the retrospective incidence (p<0.001). In total, 448 falls were registered, of which 142 were classified as directly related to sport, mostly sit-ski (132 falls, 93%) which were subsequently excluded from further analysis. Thus, 306 falls remained according to the operational definition used in the study. The mean number of falls was 2.1 (SD 2.7), with a median of 1 (min-max 0-14). Almost two-thirds of the falls (65%) occurred indoors and around half of the falls (47%) occurred during daytime (9 am to 6 pm). The most common situations for falls were wheelchair transfers, resulting in 105 falls 34% (55 [18%] to bed or another chair, 27 [9%] to car and 23 [8%] to commode), and pushing wheelchair, with 74 falls [24%] (on flat ground 18 falls [6%], on uneven surface 37 falls [12%], over gutters or curbs 24 [8%]). Additional analysis shows that 32 of the 306 falls (10%) were registered with participants having consumed alcohol. Only one (!) of the wheelchair users, reported winter weather conditions a reason for their fall, while five falls were caused by playing with dogs.

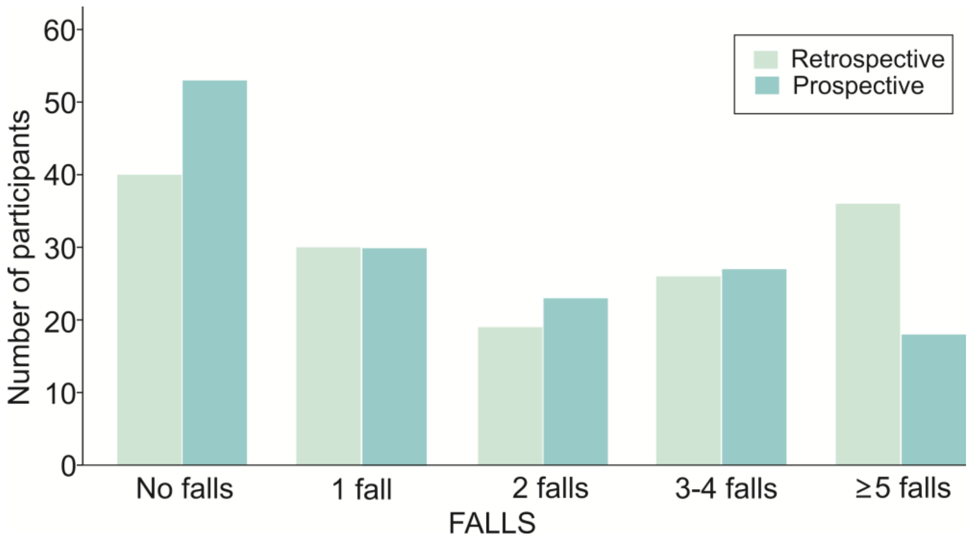

Figure 6. Distribution of retro- and prospectively reported falls of wheelchair users during one year, categorized as no fall, one fall, two falls, three to four falls, and at least five falls. In total, significantly lower number of falls were reported prospectively compared to retrospectively (p<0.001).

4.4 ASSOCIATED FACTORS AND RISK INDICATORS OF FALLS, PAPERS 2-3

In the paper on retrospectively reported falls in the total sample (paper 2), the final multivariate regression model (table 7) showed that the odds ratio of reporting recurrent falls was 2.9 times higher for ambulatory individuals compared to wheelchair users. Further, the odds ratio was 2.2 times higher for those who were able to get up from the ground by themselves compared with those who were not, and 1.9 times higher for those who exercised at least 30 minutes once a week compared with those who exercised less. With increasing age the odds ratio of recurrent falls decreased by 3% per year. In the subgroup analysis of wheelchair users, there were three significant variables in the final multivariate regression model (see table7): the odds ratio of recurrent falls was 3.1 times higher for men compared to women, with the odds ratio decreasing by 4% per year of as age increase. Further, the odds ratio of recurrent falls increased by 14% for each point increase on the SCIM III mobility sum score.

In the paper on prospectively registered falls of wheelchair users (paper 3), bivariate analysis showed that those who were working or studying and those who had a higher SCIM mobility score (i.e. more functionally independent) had higher odds ratios of recurrent falls. The final multivariate regression model (see table 7) showed that those who reported recurrent falls the previous year had 10.2 times higher odds ratio for recurrent falls the following year, which was the only significant ($p < 0.001$) risk indicator.

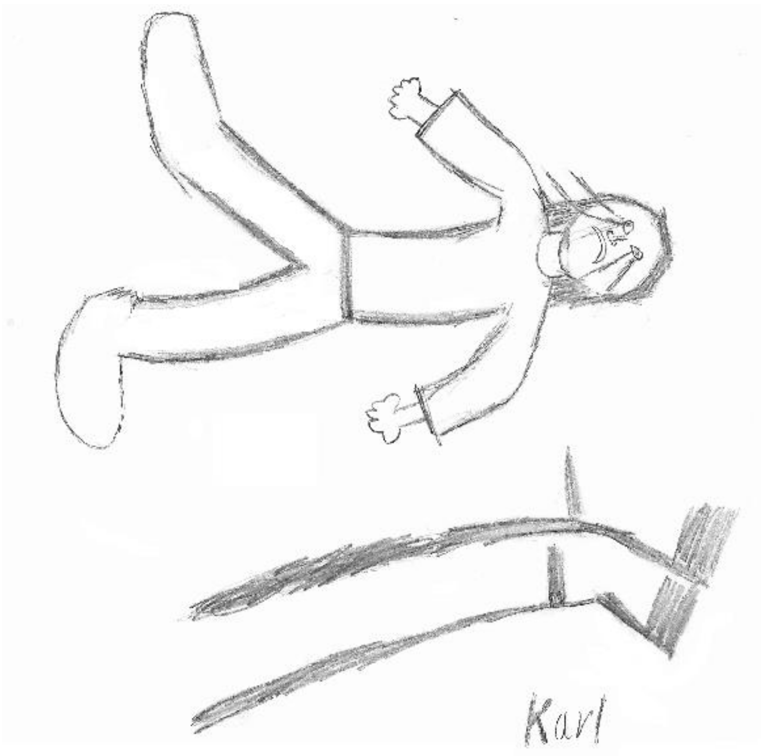

Illustration by Karl Forslund.

Table 7. Final multivariate logistic regression models consisting of age, gender and significant factors associated with recurrent (>2) falls.Displayed for total sample with retrospectieve registration of falls (paper2), and for wheelchair users with retrospective (paper 2) and prospective registration of falls (paper 3). First category is reference for categorical variables unless stated otherwise.

	Final multivariate models											
	Retrospective falls								**Prospective falls**			
	Total sample				**Wheelchair users**				**Wheelchair users**			
Variable	**β**	**OR**	**95% CI**	**p-value**	**β**	**OR**	**95% CI**	**p-value**	**β**	**OR**	**95% CI**	**p-value**
Age	0.12	0.97	0.95-0.99	**0.012**	-0.04	0.96	0.94-0.99	**0.005**	–0.007	0.99	0.96–1.02	0.641
Gender (ref. woman)	0.48	1.61	0.80-3.24	0.182	1.12	3.06	1.09-8.59	**0.033**	–0.427	0.65	0.21–2.00	
Wheelchair user or ambulatory[1]	1.08	2.93	1.43-6.03	**0.006**								
Able to get up by one-self[2] (no/yes)	0.77	2.15	1.16-3.99	**0.015**								
Exercise previous year[3] (no/yes)	0.64	1.90	1.07-3.38	**0.029**								
SCIM III Mobility[4]					0.13	1.14	1.04-1.24	**0.006**				
Previous falls 0-2/ >2[5]									2.329	10.27	4.27–24.74	< 0.001

Overall model fit (Hosmer and Lemeshow test): Chi^2=6.135, df=8, n= 223, p= 0.632 for the total sample. Overall model fit (Hosmer and Lemeshow test): Chi^2= 2.455, df= 8, n= 151, p= 0.964 for wheelchair users -retrospective registration. Overall model fit (Hosmer and Lemeshow test): $\chi 2$ = 6.272, df = 8, n = 149, p = 0.617 for wheelchair users -prospective registration.

[1]Defined as 75% wheelchair user for mobility needs/ambulatory

[2]Defined as able to get up from the ground by one-self, with-out help from another person and with-out any other aids than used at the time of fall.

[3]Regular exercise the previous year, i.e. at least 30 minutes at least once per week.

[4]Spinal Cord Injury Independence Measure version III, mobility items sum score

[5]The variable falls previous year only eligible in the multivariate regression model for prospective falls in wheelchair users

P-values <0.05 in bold.

4.5 INCIDENCE OF FALL-RELATED INJURIES (PAPERS 2 AND 3)

Fifty of the 149 wheelchair users (34%) reported at least one fall-related injury, in relation to the 96 (64%) who fell. Of the total 70 registered fall-related injuries, 47 (67%) were minor (mostly bruises, scratches or pain less than 3 days), 16 (23%) were moderate (mostly strains or sprains) and 7 (10%) were severe (6 femoral or tibia fractures and 1 concussion). Thus, 70 (23%) of the falls were injurious, and 50 (52%) of the fallers were injured to some degree. Seventeen participants (18%), of those who fell, reported seeking medical attention after falls (one participant did this twice). Four persons sustained fractures during wheelchair transfers an additional two after falling forward when driving their wheelchairs. Of these six, two fell while ill (fever or poor general health), and one due to decreased spasticity after changed medication. Moreover, one person sustained a concussion after falling backwards while pushing the wheelchair backwards.

Additional exploration of the baseline data collection of the retrospectively registered falls showed that fall-related injuries the previous year were reported by 74 (49%) of the wheelchair users, and more than one injury was reported by 10 persons. However, no classification regarding severity of injuries was performed with respect to recall bias. Further, 28% of the wheelchair users reported fractures since onset of SCI, i.e. not only during the previous year. There was a higher incidence of prospectively reported fall-related injuries among the ambulatory persons compared to the wheelchair users ($p<0.001$), when analyzing the total sample ($n=224$). However, the proportion of moderate and severe injuries was similar ($p= 0.456$) in the two subgroups (no or minor injury versus moderate or severe).

4.6 RISK INDICATORS OF FALL-RELATED INJURIES (PAPER 3)

Risk indicators of fall-related injuries were investigated in 149 wheelchair users (paper 3). In the bivariate regression model general quality of life was the only variable close to significance ($p=0.065$). The final model showed that for each units' increase in general quality of life (e.g. higher general quality of life) the odds ratio of having a fall-related injury the following year decreased by14% (OR 0.86, $p = 0.037$); please see table 8. Associated factors for fall-related injuries were not studied in the retrospective part of the study due to the high risk of recall bias.

Table 8. The initial and final multivariate logistic regression model consisting of age, gender and factors associated with no fall -related injury versus fall related injuries. First category is reference for categorical variables unless stated otherwise.

	Initial model				**Final model**			
Variable	**β**	**OR**	**95% CI**	**p-value**	**β**	**OR**	**95% CI**	**p-value**
Age	-0.00	1.00	0.98-1.02	0.956	0.00	1.00	0.98-1.03	0.943
Gender (ref woman)	-0.14	0.87	0.36-2.12	0.759	-0.16	0.86	0.35-2.07	0.729
Fall injury previous year (No/yes)	-0.52	0.59	0.30-1.19	0.138				
Quality of life[1]	-0.15	0.86	0.73-1.02	0.074	-0.15	0.86	0.74-.99	**0.037**
Depressive symptoms[2] (No/yes)	0.03	1.03	0.30 -3.48	0.965				

[1]International Spinal Cord Injury Quality of Life Basic Data Set
[2]Hospital Anxiety and Depression Scale, depression sum sore >7
Overall model fit (Hosmer and Lemeshow test): Chi^2=12.841, df=8, n=149, p=0.117
Cox & Snell R2=0.030, Nagelkerke R2=0.041
P-values <0.05 in bold.

Additional analysis showed that only three minor injuries (pain and bruises) out of 132 falls, and no moderate or severe injury, were recorded in relation to sport. Further, five moderate and four minor injuries were reported in nine of the 32 falls (10%) that were preceded by consumption of alcohol.

4.7 FALL RISK ASSESSMENTS (PAPER 4)

The Downton Fall Risk Index sum score ranged between 1 and 4 (of the possible 0-11), with a median of 2 (IQR 1). Falls the previous year were reported by 111 (74%) of the 151 participants, (see table 9). Forty-four persons (29%) were defined as having a high risk of falls (sum score ≥3), and 107 (71%) as low risk. In the low risk group, 62 of 107 (58%) had fallen after twelve months, compared to 36 of the 44 persons (82%) in the high-risk group, which can be seen in table 9. The analysis was stratified by falls the previous year. Hence, of those who had not fallen the previous year 27 of 53 persons (51%) had fallen after twelve months follow-up, compared to 85 of the 98 (87%) who had fallen the previous year.

Table 9. Cross-tabulation of number of participants who did or did not fall during one year follow-up. Number of participants is displayed as low or high risk according to Downton Fall Risk Index, and as fallen or not during the previous year according to a single item question.

	Fallen during follow-up		**Total**
Downton Fall Risk Index	**No**	**Yes**	
Low risk	45	62	107
High risk	8	36	44
Total	53	98	151
Fallen previous year			**Total**
No	26	13	39
Yes	27	85	112
Total	53	98	151

Significant variables from the previous papers of the SCIP Falls study (papers 2,3 and Jørgensen et al [81]) were analyzed with Cox survival analysis and stratified by falls the previous year. The result of the multivariate analysis showed that general quality of life scores remained significantly associated with the time to first fall (HR =0.75; 95%CI = 0.58-0.96), while HADS depression score had a p-value of 0.06 (HR = 4.00; 95% CI = 0.94-16.91) for those who had not fallen the previous year. Further, for persons who had fallen the previous year, multivariate analysis was not performed due to the low number of participants in several cells, and high p-values.

Kaplan-Meier analysis showed that time to first fall was shorter for the Downton Fall Risk Index high-risk group, (Log Rank Mantel-Cox, p=0.005) and for the group that had fallen the previous year, (Log Rank Mantel-Cox, p<0.001).

Additional analysis: Time to first fall was significantly longer for the wheelchair users compared to the ambulatory persons (Log Rank Mantel-Cox, p<0.001), please see figure 7.

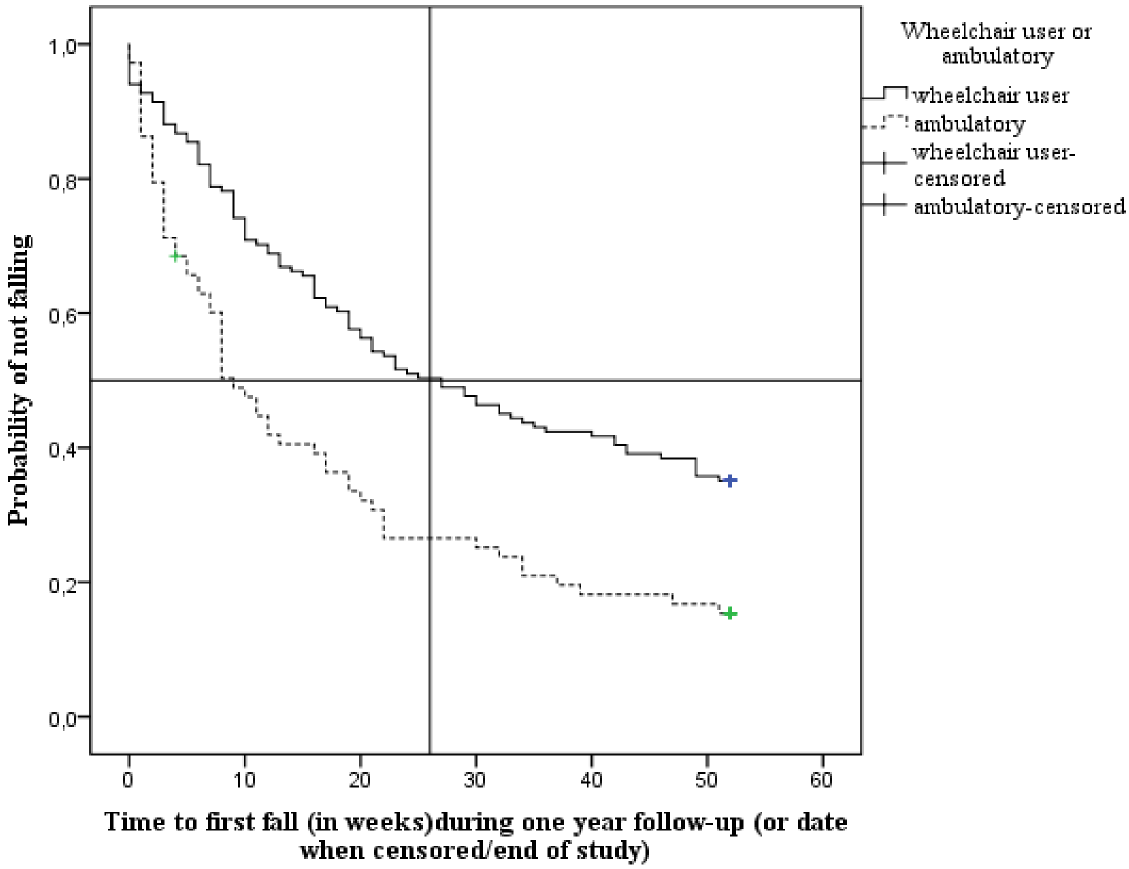

Figure 7. Kaplan Meier graph of time to first fall (in weeks) for wheelchair users (solid black) and ambulatory persons (dotted) during 52 weeks of follow-up, displayed with reference lines at half time (26 weeks), and at 50% probability of not falling.

5 GENERAL DISCUSSION

5.1 MAIN FINDINGS

This thesis on the incidence of, and risk indicators for, falls and fall-related injuries after SCI, contributes to enhancing the body of knowledge which is required for creating future strategies that may prevent falls and fall-related injuries. This project is both unique and novel in that we investigated falls in both wheelchair users and ambulatory persons, within a broad perspective on contributing factors using both retrospective and prospective design. In this section, some of the results from the included papers and manuscripts will be discussed; in a more speculative manner. For further discussion, please see paper 1-4.

The Swedish version of SCI-FCS showed, in general, similar psychometric properties as the original version, supporting the validity of the instrument. In the current study, wheelchair users reported overall low levels of concerns about falling, where pushing one's wheelchair on uneven ground or up/down slopes were the activities associated with most concerns.

Ambulatory persons reported more falls than wheelchair users in the retrospective inquiry on falls, and mode of mobility was the factor with the highest odds ratio for reporting recurrent falls. In addition, ability to get up from the ground, performing regular exercise, and younger age also resulted in a greater risk of recurrent falls for both wheelchair users and ambulatory persons. Subgroup analysis indicated that factors associated with recurrent falls differed between wheelchair users and ambulatory persons.

When investigating prospectively reported falls in wheelchair users, the incidence was higher than earlier reported, with two thirds falling at least once, and one third falling recurrently during one year. Further, one third was injured, equal to half of those who fell. Recurrent falls the previous year strongly increased the risk of recurrent falls the next year while higher quality of life reduced the risk of injuries. In total, there were 70 fall-related injuries, of these were 67% minor (mostly bruises, scratches or pain less than 3 days), 23% moderate (mostly strains or sprains) and 10% severe (six femoral or tibia fractures, and one concussion). Of the 149 participants who completed follow-up, 50 (34%) reported at least one fall-related injury.

Downton Fall Risk Index showed low accuracy for predicting falls within one year in the wheelchair users (sensitivity 37%), while the question related to falls the previous year was more accurate (sensitivity 86%). Regarding identification of those who did not fall, better predictive accuracy (sensibility 85%) was found, compared to the question related to falls the previous year (sensibility 49%).

5.2 CONCERNS ABOUT FALLING (PAPER 1)

Generally, the wheelchair users did not seem to be particularly concerned about falling when performing any of the daily activities contained in the instrument. The median SCI-FCS sum score was 21, of a possible 16-64, where a score of 16 corresponds to not being concerned about falling at all. The low level of concerns about falling can be considered as positive, but the results from paper 3 showed that persons with chronic SCI seem to fall quite frequently. The relationship between concerns about falling and falls is still ambiguous. In the present study, neither falls nor fall-related injuries the previous year were associated with the level of concerns about falling. Increased concerns about falling are in some studies related to number of falls (47, 64, 119-121) which are in contradiction to our results and others (60, 122) and the original SCI-FCS where higher levels of concerns were associated with lower number of falls (79). Interestingly, in a prospective study of elderly people, falls predicted fear of falling, which, in turn, predicted falls (123). Further, those who had problems getting up from the ground by them-selves reported more concerns about falling; a finding that is in line with the original version (79) and others (60).

In this study, those who had been injured for a longer time reported lower levels of concerns about falling, indicating that concerns about falling possibly are reduced with time, or that they learn to cope with concerns about falling when performing daily activities. Interestingly, most falls in this study occurred during transfers between wheelchair and bed/sofa/commode, e.g. activities that were associated with low levels of concerns about falling. On the other hand, activities that were associated with highest concerns about falling, pushing wheelchair on uneven surface, up/down gutters and curbs and up/down slopes did not cause that many falls, except for pushing wheelchair on uneven surface. Further, there was little difference in mean score (0.87 points on the 1-4 scale) between the item that was associated with least concerns, i.e. -pushing wheelchair on even ground (mean score 1.13), compared to the item with highest concerns-pushing wheelchair on uneven surface (mean score 2.0, corresponding to a little concerned about falling). It is unknown if this difference is of clinical importance or not, as the low Andrich thresholds indicate that the scale might benefit from collapsing the scale-steps (117).

Frequent fallers have been reported to restrict their activities, which might seem like a wise strategy to avoid falls and fall-related injuries (119). This supports the theory that participants took precautions when performing activities associated with high levels of concern such as driving outdoors. The inverse of that also appears, when they perceived the risk as low, such as when performing their daily transfers which; possibly allowing for a certain amount of inattention and/or carelessness. Another possible explanation is that many persons challenge their limits of transfer ability on a daily basis, and therefore might benefit from upgrading their technical aids, increasing their skills or strength, or even complementing with supervision or assistance of another person. Avoiding important activities due to concerns about falling, as discussed above, might impair quality of life and (124), and may in the long-term perspective increase the risk of falling although the mechanism is still under discussion (124-125).

Those who reported symptoms of depression, anxiety and fatigue also reported more concerns about falling, which possibly indicates that concerns about falling could be related to other kinds of psychological symptoms (64, 126).

How to decide if the SCI-FCS is to be considered as valid? Since there is no gold standard for measuring concerns about falling in wheelchair users with SCI, there is nothing to compare it to (criterion validity), and if such a tool was available, we would not have required another instrument. SCI-FCS score can be compared with other variables to somewhat determine its construct validity. Since knowledge in this field is scarce the question remains –"what does it really imply if SCI-FCS score corresponds to age, time since injury or level of SCI or not?" In research regarding elderly community-dwelling persons, concerns about falling has been shown to relate to age and sex, with women and older persons being more concerned (64, 127), while others, in agreement with the present study and the original version (79), found no differences (60). Nevertheless, transferring results based on elderly people to a group so different in age, sex distribution and co-morbidity can be questioned. Research regarding persons with multiple sclerosis (MS), showed that women, those who had fallen, and those who experienced greater impact of their MS symptoms during daily activities reported more fear of falling (128). Persons with MS have several problems related to mobility which are true for and common in with persons with SCI

The item-person map from the Rasch analysis showed that many items were assembled in the middle. A possible explanation is that many participants shared the same level of concerns about falling, or that the instrument could not capture the variations in level of concerns. The scale structure would probably benefit from removing some of the items (117).

Concerns about falling in wheelchair users with SCI have been studied in only a few settings, i.e. Australian, Swedish and Norwegian, thereby restricting the generalizability of the results to other cultural contexts.

5.3 FALLS (PAPERS 2 AND 3)

5.3.1 Incidence of falls and recurrent falls

When investigating retrospectively reported falls in the total sample of the study in both wheelchair users and ambulatory persons, around three quarters reported falling during the previous year, and around half reported recurrent falls. In line with earlier studies (38-41, 48, 92, 129) ambulatory persons reported more falls than wheelchair users, resulting in an incidence rate for ambulatory persons (81%) to be consistent with others reporting 40-50% falling in 6 months (39-41, 50). It is important to note that the period of surveillance influences the incidence.

Concerning the prospectively reported falls among wheelchair users, around two thirds fell, and around one third experienced recurrent falls during one year. This is significantly lower ($p<0.001$), when compared to 73% and 41% corresponding with first time and recurrent falls respectively, in the retrospective reports. Consequently, there seems to be a tendency of over-reporting falls when using retrospective reporting methods; however incidence of falls varies between years. Inconsistency of study design and length of reporting periods complicate comparison with earlier studies, but for the prospectively reported incidence it was found that the falls incidence was around twice as high as the results from Nelson et al (30% per year) (37), whilst remaining comparable to others reporting around 30% per 6 months (38, 39). The long and thorough follow-up, in combination with few drop-outs and few persons declining to participate, explains the high incidence of falls to a great extent. However, there is a risk of underestimating the incidence owing to the so called Hawthorne effect (130), i.e. the participants were influenced to avoid falls by participating in the study and consequently the registration of falls can be considered an intervention regardless of the intended observational design.

5.3.2 Associated factors and risk indicators for falls

In the retrospective study, ambulation as mode of mobility resulted in a ten times greater risk for reporting future recurrent falls. When sitting, as compared to standing, the base of support is larger and the center of mass lower which possibly contribute to lower fall rates among wheelchair users. Most ambulatory persons with SCI have impaired sensation and muscle strength function, thus reducing their balance control to varying extents. Additionally, ambulatory persons with incomplete cervical injuries have reduced function in their arms and hands, further worsening the situation by complicating the use of walking aids as well as wheelchair handling.

Regarding the association between falls and levels of function in ambulatory persons, the picture is unclear. Level of function did not differentiate the risk of falling in some studies (50, 51, 92), while those with lower level of function have been reported as more prone to falling (41, 81, 118). This is also true for persons with multiple sclerosis (MS) (122).

Ability to get up from the ground by one-self, performing regular exercise, and younger age also resulted in higher odds of recurrent falls in the retrospectively reported study that included both wheelchair users and ambulatory persons. Knowing that you can get up by your-self after a fall might lead to a greater exposure to activities with increased risk of falling. On the other hand knowing that you cannot get up by your-self might escalate concerns about falling that may lead to avoidance of activities with enhanced risk. Ability to get up, and exercise regularly, can also be regarded as a proxy for better health or a higher level of function which has previously been reported as associated with higher risk of falls in wheelchair users with SCI (37). However, level of function may have different impact depending on which sample is analyzed. In contrast to the ambulatory group, higher level of function in wheelchair users (37) seems to be naturally associated with falling since those with a lower level of function (i.e. tetraplegia), have no chance of getting up after a fall, or even protect themselves when falling.

Separate analysis of wheelchair users and ambulatory persons indicated that the factors associated with recurrent falls differed between the subgroups. Further, for the wheelchair users, different factors were associated with recurrent falls in both the retrospective and prospective parts of the study. Retrospectively, increased risk of recurrent falls was associated with male sex, younger age and better functional independence, while in the prospective part; only previous recurrent falls remained significant in the multivariate analysis. In the bivariate analysis of prospective falls, there was a similar trend as in the retrospective part, where those who were working and those with better functional independence had a higher risk of recurrent falls. Additionally, younger age was close to significance (p=0.066). As discussed above and in paper 1-3, higher functional level could lead to greater exposure for situations with high risk of falling.

Further, the telephone follow-up revealed that some of the participants, who expressed most concerns about falling, and also fell frequently, were altering between ambulation and wheelchair use and were not truly skilled at either of mobility modes. Although not analyzed in the present study, the latter assumption is in line with a study by Saunders et al (131), where ambulatory persons fell 1.4 times more than wheelchair users whereas those who used a wheelchair and ambulated equally fell five times more. In the total sample of the present study, there were a few persons (n=19 of 224) who were not classified as either 100%

ambulatory or 100% wheelchair user, which reduced the possibility of investigating this matter.

To enable further verification of incidence and risk indicators studies have to be performed by different research teams in different contexts. It is apparent, and, worth mentioning, that several of the cited studies on falls after SCI originates from the same research group in Thailand (38, 41, 43, 49-51, 54, 129).

5.3.3 Description of falls in wheelchair users

As around two thirds of the falls occurred indoors, in line with research on persons with MS (122) and only one person (!) reporting a fall due to winter conditions, the effect of seasonal variations on falls incidence might be regarded as low. On the other hand, several participants expressed that they avoided going outside, or were not able to go outdoors when there was tough weather with snow and/or ice. Due to this, the shown incidence of falls could have been reduced, which has been reported in an interview study of persons with MS (132). The winter season in Sweden 2013-2014, when the study was performed, could be regarded as mild with few short periods of snow (133). Consumption of alcohol was associated with 10% of the falls, and has previously been reported as a risk factor for subsequent injuries after SCI (57). This tendency was not confirmed in the regression analysis in the present study; however, there is risk of alcohol consumption being underreported, both at baseline, and when a fall was experienced.

5.4 FALL-RELATED INJURIES (PAPERS 2 AND 3)

5.4.1 Incidence

Around one third of all wheelchair users were injured, and around half of those who fell were injured to some extent. When comparing the incidence rate of injury among those who fell, equivalent results were yielded when compared with to other wheelchair users (37, 38) and ambulatory samples (92), but lower than ambulatory person in the SCIP Falls study (81). Further, the incidence was lower than for the retrospectively reported incidence among wheelchair users. However, the retrospectively reported incidence is probably at risk of recall bias.

Luckily most injuries (67%) were classified as minor, while 23 % were regarded as moderate and 10 % as severe. When focusing solely on moderate and severe injuries, the rate among fallers was similar among the wheelchair users and the ambulatory persons, 8% and 4% respectively. This is also equivalent to 6% found in the study by Wirz et al (92).

5.4.2 Associated factors and risk indicators

Forecasting fall-related injuries turned out to be difficult. A possible explanation might be that many falls and related injuries occur due to a combination of internal and external factors, contingent upon hazards and / or bad luck, which hampers prediction. General quality of life was the only variable close to significance in the bivariate regression model (p=0.065), and the only significant factor in the multivariate analysis, where increasing quality of life reduced the odds of having a fall-related injury. This might be due to several reasons: first, persons with low quality of life might have a higher tendency to report their injuries; second, they might have a lower capability to cope with their falls and therefore get injured to a greater extent; and third, lower quality of life can be regarded as proxy for a somewhat lower health, leading to more severe injuries. This might be in line with the findings by Saunders et al. (134), who showed that those performing less exercise were more likely to incur fall-related injuries when investigating ambulatory persons with SCI.

Interestingly, fall-related injuries were not associated with previous recurrent falls and fall-related injuries, fear or concerns about falling in this study. This is in contrast to the ambulatory sample of the SCIP Falls study, where recurrent falls and fear of falling were risk indicators of fall-related injuries. Further fear of falling was also associated with recurrent falls (81).

Alcohol consumption, at the time of the fall event, was reported prior to 10% of the falls (32 falls), and injuries were reported in nine falls of those falls (five moderate, four minor), thus indicating a similar incidence of fall-related injuries in comparison to the falls not associated with alcohol use (p=0.382). In line with Saunders et al (123), reported alcohol consumption at baseline was not associated with fall-related injuries. Nevertheless, it has earlier been shown to increase risk of subsequent injuries after SCI (57), especially in younger persons (<30 years) (42). Only three injuries (all minor), were recorded during the 142 falls directly related to sports.

5.5 FALL RISK ASSESSMENTS (PAPER 4)

In general, Downton Fall Risk Index sum scores were low (median 2, out of 11 possible). Only a few participants had vision or hearing impairments, all were classified as mentally oriented and as having limb impairments, and the number of medication was low. Together these circumstances resulted in low sum scores with little variation.

The classification of groups with high or low risk of falling could not predict future fallers but was more accurate at predicting those who did not fall. On the other hand, the single item question on falls the previous year was more accurate at predicting future fallers. Due to the strong association, (HR=3.35, $p<0.001$), between falls during the previous year and time to first fall during the follow-up, the Cox regression analyses were stratified for falls the previous year. For persons that had not fallen the previous year, the multivariate analysis indicated that those with better well-being had a reduced hazard ratio for time to first fall, as increased general quality of life reduced the hazard ratio, while more symptoms of depression had the tendency to increase it ($p=0.06$). Multivariate analysis could unfortunately not be performed for those who had not fallen the previous year, owing to the low number of participants in each cell and high p-values for the tested factors.

The sensitivity of a fall risk assessment is important in order to assess effects of implemented fall-prevention measures. When trying to predict falls in this sample of community-dwelling wheelchair users with SCI, the single item question on falls the previous year was more accurate than the Downton Fall Risk Index. Classifying a person falsely as having a low risk of falling might be devastating if needed precautions will not be executed. Further, for economic reasons it is important that not too many persons are falsely classified as having a high risk of falling, which could induce the implementation of unnecessary preventive measures, despite it not being harmful to the patients.

Despite the correctness of a fall risk assessment, it remains only a snapshot of the risk of falls which may be altered within days or hours. For example, for persons with SCI classified by Downton Fall Risk Index this usually means that medication can change, while most other variables are relatively stable.

5.6 METHODOLOGICAL CONSIDERATIONS

5.6.1 Internal validation

5.6.1.1 Definition of wheelchair use and ambulation

Drawing the line between wheelchair use and ambulation as primary mode of mobility was rather difficult, and three categories were considered (wheelchair users, ambulatory and those who used both) at the start of the study. With respect to the characteristics of the included participants (19/224 participants reported both ambulating and using a wheelchair), whilst maintaining maximal statistical power, we decided to only use two categories.

During the planning of the study, definitions for mode of mobility by SCIM III (82), Hoffer (135) and Boswell Ruys et al (79) were discussed. Boswell-Ruys et al (79) used the definition of wheelchair use for at least 75% of the mobility needs in their study concerning SCI-FCS.

Considering the latter, we also decided on using 75% of the mobility needs for classifying ambulatory persons. The five participants in paper 2 who reported equal use, were all classified as ambulatory after discussion in the SCIP Falls expert group. When discussing mode of mobility several interesting issues were revealed, and the participants who combined ambulation and wheelchair use were a rather heterogeneous group. Some tried to maximize their ambulation and considered the use of a wheelchair as stigmatizing, while others thought the opposite and used a wheelchair because they were ashamed of how they looked when walking. Moreover, several persons reported that they used their wheelchair in order to avoid pain. Further, there was a discussion if the classification should be based on maximal capacity or everyday performance. At the end we decided that everyday life was the main focus of interest in this study and the classification was set accordingly.

Recent studies that have been published after the start of this project used other classifications such as the percentage of time using a wheelchair to get around (none, half the time or less, or more than half the time) and to be able to propel their wheelchairs independently (131). Others used a criterion of wheelchair mobility as the primary means of mobility for more than 50 per cent of their weekly activity needs (20). Of course, the results of the study could have been slightly different with another classification of mode of mobility.

5.6.1.2 Definitions of falls and recurrent falls

There were two definitions of falls that we discussed; they were proposed by ProFaNe's and Nelson et al's where wheelchair-related falls were defined as "when a wheelchair user accidentally dropped to the floor from the wheelchair or the wheelchair tipped over even if the person remained seated" (37). At the end we concluded that the definition proposed by ProFaNe was used in this study, since the one by Nelson et al. is fully subsumed.

Extensive discussions were held in the SCIP Falls group regarding the choice of cut-off for the dichotomization of falls, i.e. whether 0/1, 0-1/>1, or 0-2/>2 should be operationalized. Since we assumed falls to be common, a dichotomization of 0/1 falls, as previously used in samples with MS and SCI (92, 111, 136), did not seem convenient. The main focus of interest was recurrent fallers due to the assumed increased risk of fall-related injuries of those who fall frequently. However, there was also a discussion, related to the idea that those who fall most probably had learned how to avoid injuries. Considering fall incidence in previous studies (37, 38, 92) and the long registration period we ended up with defining recurrent falls as more than two falls, as previously used in polio and MS samples (89, 128) . With this definition we expected the proportion of low frequent and recurrent fallers to be around 50:50. Another alternative for the dichotomy of falls was 0-1/>1 (137-138), which has become more commonly used over the years since the start of the study, especially in research regarding persons with Parkinsons disease (110, 139-144). However we wanted to capture those who fell more often; we therefore used the 0-2/>2 as a more robust dichotomization of falls since the risk of recall bias when using a classification based on only one fall could not be eliminated, especially in the absence of injury.

5.6.1.3 Definition of fall-related injuries

Fall-related injuries were self-reported, which could inevitably lead to under, or over, reporting of injuries. During the systematic telephone follow-up, participants described their injuries and their contact within the system of care; some of them were even admitted for a short period of rehabilitation at the included SCI units. Nevertheless, severe injuries were not confirmed by checking medical records which is recommended by ProFaNe (30), therefore the absence of this process aspect should be considered a limitation. Further, in some cases it proved to be difficult to classify soft tissue injuries. The latter is essential in this group since persons with SCI often have impaired sensibility and circulation that may, reduce the healing process. However, confirmation from medical records was not feasible in the present study

5.6.1.4 Registration of falls

In the present study, falls were registered prospectively with a new unique sms-based system that proved to be user-friendly and feasible for both participants and researchers. This system was a prerequisite for frequent check-ups during a long period of time, resulting in an exclusive data base on falls in persons with SCI. Adherence to answering all sms's and the associated drop-out rates were much better than expected, which may indicate that participants did not feel disturbed, and/or regarded the study as important. Until now, no other studies with comparable data collection methods for falls registration have been found (144). Concerning other e-tools, interactive tele-medicine techniques using smartphones have been used to monitor falls and to alarm staff after falls (145).

When planning the design of the follow-up procedure, the use of a fall diary was considered, but with such a long registration period we were afraid to increase the burden on participants, which may inadvertently increase the risk of drop-outs. Several participants asked for the possibility to report their falls through a web page or smartphone application. This was however not possible at the time but might be an option in the future. Such a system might have been detrimental in that there might be a risk of losing those, such as elderly, who might not be familiar with smart phones and other technological advances. Through this project we showed that elderly persons did not deny participation due to the study design. In fact, several of them took the opportunity to learn how to use the sms function.

A one-year registration period is recommended by Profane when studying falls, but long studies with close follow-up are expensive and time-consuming, as well as demanding for participants. For the wheelchair users, around 80% of fallers would have been detected with a 6 months follow-up (77 of the 98 who had fallen after 12 months). However, by enrolling participants continuously during the year, possible seasonal variation might be yet captured. With no seasonal effects found in this study, future endeavors may consider using a shorter registration period in order to reduce the burden on participant, as well as financial resources.

5.6.1.5 Statistics

Among the wheelchair users, there were only two drop-outs in the prospective study after 4.5 and 8 months respectively, and only very few missing items in the assessments and questionnaire, except for two tests in paper 2 (T-shirt test and Timed Stands Test). Analyzing falls as a dichotomous variable is common in research despite of the inevitable loss of information. We are aware that greater statistical power could have been achieved with a linear regression analysis. The choice of using logistic regression instead of linear was due to the skewed data with a few individuals reporting a very high number of falls in the retrospective part of the study (paper 2). When performing the prospective part (paper 3), we chose to keep the method in order to enable comparison between papers.

5.6.2 External validation

External validation concerns the generalizability of the sample and the results to other samples/populations. Rehab Station / Spinalis unit and Sunnaas RH have a long tradition of systematic life-long follow-up after SCI, embedded within well-established systems with chains of care, which minimize the risk of missing persons with SCI within the catchment areas. All persons included in the medical records at the two sites are offered life-long SCI follow-up, but there is a risk that persons with no perceived problems, as well as those with the greatest problems do not comply with scheduled visits. However there was a low proportion (5-10%) of persons who declined participation and no differences with respect to age, gender, time since injury, level and extent of injury were observed between those who declined or were excluded and those who participated in the study. This thesis is based, approximately, on a one-year cohort of yearly follow-ups at Rehab Station/Spinalis and Sunnaas RH and therefore we consider the sample to be fairly representative.

Persons having their SCI for less than a year were not included as the first year after incurring a SCI is very special and overwhelming in many ways; with time most persons adapt to, and learn to manage the new living condition. Therefore, the results of the study are not considered generalizable to persons with a recent SCI. In addition, the decision not to include persons with the highest motor complete injuries was taken as they need assistance from another person in several daily activities such as transfers, which may influence the risk and causes of falls.

6 CLINICAL IMPLICATIONS

The high risk of falls and their eventual negative consequences, have to be discussed at the SCI units, both during primary rehabilitation as well as during life-long follow-up. Simply screening of previous falls and concerns about falling might guide staff to investigate the need of further actions when trying to target those who fall the most and/or are most concerned. However, this thesis showed that the activities with highest perceived risk of falling did not result in most falls. This indicates that the risk of falling is difficult to estimate for persons with SCI; therefore a special focus ought to be on preventing falls in persons living on their own and those who are unable to get up by themselves. Striving to avoid unnecessary falls and related injuries during everyday activities is of great importance. Nevertheless alongside autonomy in everyday situations is a person’s right to risk.

Apart from the importance to acquire the ability to get up from the ground by one-self, or learn how to instruct somebody to help one-self, it is further important to learn how to fall “safely”. Many of the falls in this study occurred during transfers; thus, there seem to be a need for improved strategies in order to reduce the number of falls as transfers are unavoidable. In the follow-up after falls, some participants in the study recommended fixating the wheelchair to the bed when transferring for example. Improved transfer skills and muscle strength, by not compromising “shoulder safety”, could therefore be of great importance. Furthermore, some persons might be provided with alarms, and/or benefit from up-graded technical aids, such as sliding boards. However, it is a well-known challenge for physiotherapists and occupational therapist to fit every individual with the right equipment at the right time, which is further complicated by the fact that circumstances can change fast due to e.g. secondary conditions. The required change of attitudes regarding the use of technical aids is complicated as freedom from technical aids and assistance from other persons can be regarded as a sign of independence. In addition, clinical experience shows that coping with the need for new technical aids and/or assistance/surveillance from somebody else can be hard for a person who has for a long time fought for independence.

There is a high risk that those who are feeling anxious or depressed are also concerned about falling irrespective of their falling behavior (64,126) Therefore, screening of concerns about falling is important in these cases. On the other hand, because concerns about falling seem to be related to anxiety and depression, screening of concerns about falling might give a hint towards the need of further screening of anxiety and depression.

7 IMPLICATIONS FOR FUTURE RESEARCH

This thesis has shown that wheelchair users with SCI fall to a great extent, that their falls and related injuries are difficult to predict, and, however, they are not especially concerned about falling. The results also show that minor fall-related injuries are common and severe injuries are fortunately rare. Nevertheless, for persons sustaining a fracture it always remain one fracture too much. Since persons with chronic SCI sustain several secondary consequences during their life-time, it would be of great importance to know how the problem with falls is regarded among persons with SCI, compared to other problems. This is important in order to prioritize the targets for future rehabilitation as well as development of fall prevention strategies. The investigation of the latter point could be performed by qualitative interviews either individually or in focus groups, or by questionnaires e.g. to all persons attending their annual SCI check-ups. It would also be of great interest to simply ask persons with SCI about their best ways and strategies of avoiding falls in a prospect study.

Another area of interest for future studies is around the persons who vary between wheelchair use and ambulation as mode of mobility. Based on clinical experience, they are often not truly skilled at either due to problems such as reduced hand function and severe spasticity. Using their wheelchair more might reduce the risk of falling, but on the other hand, keeping the ambulatory capacity as good as possible requires exercise, therefore causing a dilemma.

The method of recording falls by sms is highly recommended in future studies of falls and related injuries, possibly with also an option to report the circumstances around the falls by using a smartphone application which could reduce the telephone follow-ups for researchers. However tempting with an automatic report function for falls, the frequent telephone contact with participants in the present study secured the quality of the data. Further, the sms interface continuously alerted participants could also be used for other purposes such as reminding to change body position in order to avoid pressure ulcers or performing an exercise program for shoulder rehabilitation.

How to best prevent falls, and especially fall-related injuries, is beyond the scope of this thesis, but strategies such as exercise programs including balance and strength training, developed for elderly (31) have shown to be effective in reducing falls and fractures. Further, restriction of medication has not shown unambiguous effect, while a gradual reduction of medication for anxiety and depression was beneficial (31). The effect of these interventions could also be tested for persons with SCI in the future.

In order to evaluate the results of future interventions, regarding both clinical work and research in the area, it is of great importance to continue the struggle for valid, reliable and feasible instruments for persons with SCI.

8 MAIN CONCLUSIONS

Falls and recurrent falls were common among persons with SCI, with ambulatory persons falling more than wheelchair users. The incidence of falls in wheelchair users was twice as high as in previous studies, as around two thirds fell during one year. Further, fall-related injuries were common and difficult to predict, but luckily most injuries were minor. One concussion and six fractures occurred, (all in the legs), which is equivalent to injury rates in elderly. Previous fall events predisposed individuals to future falls, and asking for previous falls was a better way of identifying persons who will fall, compared to using the high risk definition by Downton Fall Risk Index. On the other hand, the index was better at predicting those who did not fall.

The Swedish version of the SCI-FCS showed similar properties as the original, supporting the validity of the instrument. Wheelchair users in the study were in general not concerned about falling when performing every day activities such as pushing their wheelchair on uneven surface, and going up/down gutters and curbs, while pushing it up/down slopes was associated with most concerns. However, most falls occurred during transfers to/from the wheelchair and while pushing wheelchair. Interestingly, they are not concerned about falling in situations where they actually fall.

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10 REFERENCES

1. Kirshblum SC, Burns SP, Biering-Sorensen F, Donovan W, Graves DE, Jha A, et al. International standards for neurological classification of spinal cord injury (revised 2011). J Spinal Cord Med. 2011;34(6):535-546.

2. Bjornshave Noe B, Mikkelsen EM, Hansen RM, Thygesen M, Hagen EM. Incidence of traumatic spinal cord injury in Denmark, 1990-2012: a hospital-based study. Spinal Cord. 2015;53(6):436-440.

3. Chen Y, He Y, DeVivo MJ. Changing demographics and injury profile of new traumatic spinal cord injuries in the United States, 1972-2014. Arch Phys Med Rehabil. 2016;97(10):1610-1619.

4.Ahoniemi E, Alaranta H, Hokkinen EM, Valtonen K, Kautiainen H. Incidence of traumatic spinal cord injuries in Finland over a 30-year period. Spinal Cord. 2008;46(12):781-784.

5.Kirshblum SC, Waring W, Biering-Sorensen F, Burns SP, Johansen M, Schmidt-Read M, et al. Reference for the 2011 revision of the International standards for neurological classification of spinal cord injury. J Spinal Cord Med. 2011;34(6):547-354.

6. International Standards for Neurological classification of SCI (ISNSCI) worksheet http://asia-spinalinjury.org/wp-content/uploads/2016/02/International_Stds_Diagram_Worksheet.pdf2016.

7. Scivoletto G, Di Donna V. Prediction of walking recovery after spinal cord injury. Brain research bulletin. 2009;78(1):43-51.

8.Jazayeri SB, Beygi S, Shokraneh F, Hagen EM, Rahimi-Movaghar V. Incidence of traumatic spinal cord injury worldwide: a systematic review. European spine journal. 2015;24(5):905-918.

9.Divanoglou A, Levi R. Incidence of traumatic spinal cord injury in Thessaloniki, Greece and Stockholm, Sweden: a prospective population-based study. Spinal Cord. 2009;47(11):796-801.

10. Hagen EM, Eide GE, Rekand T, Gilhus NE, Gronning M. A 50-year follow-up of the incidence of traumatic spinal cord injuries in Western Norway. Spinal Cord. 2010;48(4):313-318.

11.Lasfargues JE, Custis D, Morrone F, Carswell J, Nguyen T. A model for estimating spinal cord injury prevalence in the United States. Paraplegia. 1995;33(2):62-68.

12 .Lee BB, Cripps RA, Fitzharris M, Wing PC. The global map for traumatic spinal cord injury epidemiology: update 2011, global incidence rate. Spinal Cord. 2014;52(2):110-116.

13. Stover SL, Fine PR. The epidemiology and economics of spinal cord injury. Paraplegia. 1987;25(3):225-228.

14. O'Connor PJ. Prevalence of spinal cord injury in Australia. Spinal Cord. 2005;43(1):42-46.

15.Dahlberg A, Kotila M, Leppanen P, Kautiainen H, Alaranta H. Prevalence of spinal cord injury in Helsinki. Spinal Cord. 2005;43(1):47-50.

16. Knutsdottir S. Spinal cord injuries in Iceland 1973-1989. A follow up study. Paraplegia. 1993;31(1):68-72.

17. DeVivo MJ, Chen Y. Trends in new injuries, prevalent cases, and aging with spinal cord injury. Arch Phys Med Rehabil. 2011;92(3):332-338.

18. DeVivo MJ. Sir Ludwig Guttmann Lecture: trends in spinal cord injury rehabilitation outcomes from model systems in the United States: 1973-2006. Spinal Cord. 2007;45(11):713-721.

19. Bjornshave Noe B, Mikkelsen EM, Hansen RM, Thygesen M, Hagen EM. Incidence of traumatic spinal cord injury in Denmark, 1990-2012: a hospital-based study. Spinal Cord. 2014;53(4):436-440

20. Kirby RL, Worobey LA, Cowan R, Pedersen JP, Heinemann AW, Dyson-Hudson TA, et al. Wheelchair Skills Capacity and Performance of Manual Wheelchair Users With Spinal Cord Injury. Arch Phys Med Rehabil. 2016;97(10):1761-1769.

21. Burns SP, Golding DG, Rolle WA, Jr., Graziani V, Ditunno JF, Jr. Recovery of ambulation in motor-incomplete tetraplegia. Arch Phys Med Rehabil. 1997;78(11):1169-1172.

22. Chhabra HS. ISCoS Textbook on comprehensive management of spinal cord injuries. Wolters Kluwer: New Delhi, India; 2015.

23. Adriaansen JJ, Post MW, de Groot S, van Asbeck FW, Stolwijk-Swuste JM, Tepper M, et al. Secondary health conditions in persons with spinal cord injury: a longitudinal study from one to five years post-discharge. J Rehabil Med. 2013;45(10):1016-1022.

24. Krause JS, Carter RE, Pickelsimer EE, Wilson D. A Prospective Study of Health and Risk of Mortality After Spinal Cord Injury. Arch Phys Med Rehabil. 2008;89(8):1482-1491.

25.Noreau L, Proulx P, Gagnon L, Drolet M, Laramee MT. Secondary impairments after spinal cord injury: a population-based study. Am J Phys Med Rehabil. 2000;79(6):526-535.

26.Lazo MG, Shirazi P, Sam M, Giobbie-Hurder A, Blacconiere MJ, Muppidi M. Osteoporosis and risk of fracture in men with spinal cord injury. Spinal Cord. 2001;39(4):208-214.

27. Karapolat I, Karapolat HU, Kirazli Y, Capaci K, Akkoc Y, Kumanlioglu K. Longitudinal study of bone loss in chronic spinal cord injury patients. J Phys Ther Sci. 2015;27(5):1429-1433.

28. Guideline for the prevention of falls in older persons. American Geriatrics Society, British Geriatrics Society, and American Academy of Orthopaedic Surgeons Panel on Falls Prevention. J Am Geriatr Soc. 2001;49(5):664-672.

29. Lord SR, Menz HB, Sherrington C. Home environment risk factors for falls in older people and the efficacy of home modifications. Age Ageing. 2006;35 Suppl 2:ii55-ii9.

30. Lamb SE, Jorstad-Stein EC, Hauer K, Becker C. Development of a common outcome data set for fall injury prevention trials: the Prevention of Falls Network Europe consensus. J Am Geriatr Soc. 2005;53(9):1618-1622.

31.Gillespie L D RMC, Gillespie W J, Sherrington C, Gates S, Clemson L M, Lamb S E. Interventions for preventing falls in older people living in the community. Cochrane Database of Systematic Reviews. 2012;John Wiley & Sons, Ltd (CD007146).

32. Talbot LA, Musiol RJ, Witham EK, Metter EJ. Falls in young, middle-aged and older community dwelling adults: perceived cause, environmental factors and injury. BMC public health. 2005;5:86.

33. Tinetti ME, Speechley M, Ginter SF. Risk factors for falls among elderly persons living in the community. N Engl J Med. 1988;319(26):1701-1707.

34. Bloem BR, Grimbergen YA, Cramer M, Willemsen M, Zwinderman AH. Prospective assessment of falls in Parkinson's disease. J Neurol. 2001;248(11):950-958.

35. Painter JA, Elliott SJ, Hudson S. Falls in community-dwelling adults aged 50 years and older: prevalence and contributing factors. J Allied Health. 2009;38(4):201-207.

36. Mazumder R, Murchison C, Bourdette D, Cameron M. Falls in people with multiple sclerosis compared with falls in healthy controls. PloS one. 2014;9(9):e107620.

37.Nelson AL, Groer S, Palacios P, Mitchell D, Sabharwal S, Kirby RL, et al. Wheelchair-Related Falls in Veterans With Spinal Cord Injury Residing in the Community: A Prospective Cohort Study. Arch Phys Med Rehabil. 2010;91(8):1166-1173.

38.Amatachaya S, Wannapakhe J, Arrayawichanon P, Siritarathiwat W, Wattanapun P. Functional abilities, incidences of complications and falls of patients with spinal cord injury 6 months after discharge. Spinal Cord. 2011;49(4):520-524.

39. Matsuda PN, Verrall AM, Finlayson ML, Molton IR, Jensen MP. Falls Among Adults Aging With Disability. Arch Phys Med Rehabil. 2015;96(3):464-471.

40. Brotherton SS, Krause JS, Nietert PJ. Falls in individuals with incomplete spinal cord injury. Spinal Cord. 2007;45(1):37-40.

41. Phonthee S, Saengsuwan J, Siritaratiwat W, Amatachaya S. Incidence and Factors Associated With Falls in Independent Ambulatory Individuals With Spinal Cord Injury: A 6-Month Prospective Study. Phys Ther. 2013;93(8):1061-1072.

42. Saunders LL, Krause JS. Injuries and Falls in an Aging Cohort with Spinal Cord Injury: SCI Aging Study. Top Spinal Cord Inj Rehabil. 2015;21(3):201-207.

43. Srisim K, Amatachaya S, Saengsuwan J. Functional assessments for predicting multiple falls in independent ambulatory patients with spinal cord injury. J Spinal Cord Med. 2015;38(4):439-445.

44. Poss JW, Hirdes JP. Very Frequent Fallers and Future Fall Injury: Continuous Risk Among Community-Dwelling Home Care Recipients. J Aging Health. 2015.

45. Bergland A, Wyller TB. Risk factors for serious fall related injury in elderly women living at home. Inj Prev. 2004;10(5):308-313.

46.Nevitt MC, Cummings SR, Kidd S, Black D. Risk-factors for recurrent nonsyncopal falls-a prospective study.J Am Med Assoc. 1989;261(18):2663-2668.

47. Brotherton SS, Krause JS, Nietert PJ. A pilot study of factors associated with falls in individuals with incomplete spinal cord injury. J Spinal Cord Med. 2007;30(3):243-250.

48.Nelson A, Ahmed S, Harrow J, Fitzgerald S, Sanchez-Anguiano A, Gavin-Dreschnack D. Fall-related fractures in persons with spinal cord impairment: a descriptive analysis. SCI nursing. 2003;20(1):30-37.

49. Amatachaya S, Pramodhyakul W, Wattanapan P, Eungpinichpong W. Ability of obstacle crossing is not associated with falls in independent ambulatory patients with spinal cord injury. Spinal Cord. 2015;53(8):598-603.

50.Phonthee S, Saengsuwan J, Amatachaya S. Falls in independent ambulatory patients with spinal cord injury: incidence, associated factors and levels of ability. Spinal Cord. 2013;51(5):365-368.

51. Srisim K, Saengsuwan J, Amatachaya S. Functional assessments for predicting a risk of multiple falls in independent ambulatory patients with spinal cord injury. J Spinal Cord Med. 2015;38(4):439-445.

52.Chen W-Y, Jang Y, Wang J-D, Huang W-N, Chang C-C, Mao H-F, et al. Wheelchair-Related Accidents: Relationship With Wheelchair-Using Behavior in Active Community Wheelchair Users. Arch Phys Med Rehabil. 2011;92(6):892-898.

53. Kirby RL, Ackroyd-Stolarz SA, Brown MG, Kirkland SA, MacLeod DA. Wheelchair-related accidents caused by tips and falls among noninstitutionalized users of manually propelled wheelchairs in Nova Scotia. Am J Phys Med Rehabil. 1994;73(5):319-330.

54.Wannapakhe J, Arrayawichanon P, Saengsuwan J, Amatachaya S. Medical complications and falls in patients with spinal cord injury during the immediate phase after completing a rehabilitation program. J Spinal Cord Med. 2015;38(1):84-90.

55. Gavin-Dreschnack D, Nelson A, Fitzgerald S, Harrow J, Sanchez-Anguiano A, Ahmed S, et al. Wheelchair-related falls: current evidence and directions for improved quality care. J Nurs Care Qual. 2005;20(2):119-127.

56. Krause JS. Factors associated with risk for subsequent injuries after traumatic spinal cord injury. Arch Phys Med Rehabil. 2004;85(9):1503-1508.

57. Krause JS. Risk for Subsequent Injuries After Spinal Cord Injury: A 10-Year Longitudinal Analysis. Arch Phys Med Rehabil. 2010;91(11):1741-1746.

58. Yardley L, Smith H. A prospective study of the relationship between feared consequences of falling and avoidance of activity in community-living older people. Gerontologist. 2002;42(1):17-23.

59. Legters K. Fear of falling. Phys Ther. 2002;82(3):264-272.

60. Tinetti ME, Richman D, Powell L. Falls Efficacy as a measure of fear of falling. J Gerontol. 1990;45(6):239-243.

61. Tinetti ME, Powell L. Fear of falling and low self-efficacy: a case of dependence in elderly persons. J Gerontol. 1993;48 Spec No:35-38.

62. Jorstad EC, Hauer K, Becker C, Lamb SE. Measuring the psychological outcomes of falling: a systematic review. J Am Geriatr Soc. 2005;53(3):501-510.

63. Bandura A. Self-efficacy mechanism in human agency. Am Psychol. 1982;37(2):122-47.

64.Delbaere K, Close JC, Mikolaizak AS, Sachdev PS, Brodaty H, Lord SR. The Falls Efficacy Scale International (FES-I). A comprehensive longitudinal validation study. Age Ageing. 2010;39(2):210-216.

65.Yardley L, Beyer N, Hauer K, Kempen G, Piot-Ziegler C, Todd C. Development and initial validation of the Falls Efficacy Scale-International (FES-I). Age Ageing. 2005;34(6):614-619.

66. Hill H, McMeekin P, Parry SW. Does the falls efficacy scale international version measure fear of falling: a reassessment of internal validity using a factor analytic approach. Age Ageing. 2014;43(4):559-562.

67.Fuzhong L, McAuley E, Fisher KJ, Harmer P, Chaumeton N, Wilson NL. Self-efficacy as a mediator between fear of falling and functional ability in the elderly. J Aging Health. 2002;14(4):452-466.

68. Moore DS, Ellis R. Measurement of fall-related psychological constructs among independent-living older adults: a review of the research literature. Aging Ment Health. 2008;12(6):684-699.

69.Delbaere K, Crombez G, Vanderstraeten G, Willems T, Cambier D. Fear-related avoidance of activities, falls and physical frailty. A prospective community-based cohort study. Age Ageing. 2004;33(4):368-373.

70. Kendrick D, Kumar A, Carpenter H, Zijlstra GA, Skelton DA, Cook JR, et al. Exercise for reducing fear of falling in older people living in the community. Cochrane Database Syst Rev. 2014 Nov 28;11:Cd009848.

71. Vassallo M, Poynter L, Sharma JC, Kwan J, Allen SC. Fall risk-assessment tools compared with clinical judgment: an evaluation in a rehabilitation ward. Age Ageing. 2008;37(3):277-281.

72. Meyer G, Kopke S, Haastert B, Muhlhauser I. Comparison of a fall risk assessment tool with nurses' judgement alone: a cluster-randomised controlled trial. Age Ageing. 2009;38(4):417-423.

73.Rosendahl E, Lundin-Olsson L, Kallin K, Jensen J, Gustafson Y, Nyberg L. Prediction of falls among older people in residential care facilities by the Downton index. Aging Clin Exp Res. 2003;15(2):142-147.

74. Downton JH, Andrews K. Prevalence, characteristics and factors associated with falls among the elderly living at home. Ageing. 1991;3(3):219-228.

75. Oliver D, Britton M, Seed P, Martin FC, Hopper AH. Development and evaluation of evidence based risk assessment tool (STRATIFY) to predict which elderly inpatients will fall: case-control and cohort studies. BMJ. 1997;315(7115):1049-1053.

76.Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality-of-life measures- litterature review and proposed guidelines. J Clin Epidemiol. 1993;46(12):1417-1432.

77. Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. Spine. 2000;25(24):3186-3191.

78. Mokkink LB, Terwee CB, Patrick DL, Alonso J, Stratford PW, Knol DL, et al. The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. Qual Life Res. 2010;19(4):539-549.

79. Boswell-Ruys CL, Harvey LA, Delbaere K, Lord SR. A Falls Concern Scale for people with spinal cord injury (SCI-FCS). Spinal Cord. 2010;48(9):704-709.

80. Jørgensen V. Falls in ambulatory individuals with spinal cord injury: incidence, risk factors and perceptions of falls. [dissertation of the internet]. Stockholm: Karolinska Institutet; 2016.[cited 2016 Oct 28] Available at https://openarchive.ki.se/xmlui/handle/10616/1/browse?value=J%C3%B8rgensen%2C+Vivien&type=author

81. Jorgensen V BFE, Opheim A, Franzén E, Wahman K, Hultling C, Seiger Å, Ståhle A, Stanghelle JK, Skavberg Roaldsen K. Falls and fear of falling are predictors of future falls and related injuries in ambulatory individuals with spinal cord injury: a longitudinal observational study. J Physiother. [Accepted for publication]

82.Itzkovich M, Gelernter I, Biering-Sorensen F, Weeks C, Laramee MT, Craven BC, et al. The Spinal Cord Independence Measure (SCIM) version III: reliability and validity in a multi-center international study. Disabil Rehabil. 2007;29(24):1926-1933.

83.Itzkovich M, Tamir A, Philo O, Steinberg F, Ronen J, Spasser R, et al. Reliability of the Catz-Itzkovich Spinal Cord Independence Measure assessment by interview and comparison with observation. Am J Phys Med Rehabil. 2003;82(4):267-272.

84. Glass CA, Tesio L, Itzkovich M, Soni BM, Silva P, Mecci M, et al. Spinal Cord Independence Measure, version III: applicability to the UK spinal cord injured population. J Rehabil Med. 2009;41(9):723-728.

85. Caspersen CJ, Powell KE, Christenson GM. Physical activity, exercise, and physical fitness: definitions and distinctions for health-related research. Public Health Reports. 1985;100(2):126-131.

86. Sweden Phao. Available at http://www.folkhalsomyndigheten.se/about-folkhalsomyndigheten-the-public-health-agency-of-sweden/ http://www.folkhalsomyndigheten.se/nationella-folkhalsoenkaten/ accessed December 1, 2012.

87. Konig N, Taylor WR, Armbrecht G, Dietzel R, Singh NB. Identification of functional parameters for the classification of older female fallers and prediction of 'first-time' fallers. J R Soc Interface. 2014;11(97):20140353.

88.O'Loughlin JL, Robitaille Y, Boivin JF, Suissa S. Incidence of and risk factors for falls and injurious falls among the community-dwelling elderly. A Jo Epidemiol. 1993;137(3):342-354.

89. Hoang PD, Cameron MH, Gandevia SC, Lord SR. Neuropsychological, balance, and mobility risk factors for falls in people with multiple sclerosis: a prospective cohort study. Arch Phys Med Rehabil. 2014;95(3):480-486.

90. Nyberg L, Gustafson Y. Using the Downton index to predict those prone to falls in stroke rehabilitation. Stroke. 1996;27(10):1821-1824.

91. Nordell E, Andreasson M, Gall K, Thorngren K-G. Evaluating the Swedish version of the Falls Efficacy Scale-International (FES-I). Adv Physiother. 2009;11(2):81-87.

92. Wirz M, Muller R, Bastiaenen C. Falls in persons with spinal cord injury: validity and reliability of the Berg Balance Scale. Neurorehabil Neural Repair. 2010;24(1):70-77.

93. Roaldsen KS. Test-retest reliability at the item level and total score level of the Norwegian version of the Spinal Cord Injury Falls Concern Scale (SCI-FCS). J Spinal Cord Med 2016;39(3):317-326

94.Charlifue S, Post MW, Biering-Sorensen F, Catz A, Dijkers M, Geyh S, et al. International Spinal Cord Injury Quality of Life Basic Data Set. Spinal Cord. 2012;50(9):672-675.

95. Post MW, Adriaansen JJ, Charlifue S, Biering-Sorensen F, van Asbeck FW. Good validity of the international spinal cord injury quality of life basic data set. Spinal Cord. 2016;54(4):314-318.

96. Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. Acta Psychiatr Scand. 1983;67(6):361-370.

97. Lisspers J, Nygren A, Söderman E. Hospital Anxiety and Depression Scale (HAD): some psychometric data for a Swedish sample. Acta Psychiatr Scand. 1997;96(4):281-286.

98. Mykletun A, Stordal E, A. D. Hospital Anxiety and Depression (HAD) scale: factor structure, item analyses and internal consistency in a large population. Br J Psychiatry. 2001;179(6):540-544.

99.Muller R, Cieza A, Geyh S. Rasch analysis of the Hospital Anxiety and Depression Scale in spinal cord injury. Rehabil Psychol. 2012;57(3):214-223.

100. Woolrich RA, Kennedy P, Tasiemski T. A preliminary psychometric evaluation of the Hospital Anxiety and Depression Scale (HADS) in 963 people livingwith a spinal cord injury. Psychol Health Med. 2006;11(1):80-90.

101. Krupp LB, LaRocca NG, Muir-Nash J, Steinberg AD. The fatigue severity scale: Application to patients with multiple sclerosis and systemic lupus erythematosus. Arch Neurol. 1989;46(10):1121-1123.

102. Lerdal A, Wahl AK, Rustoen T, Hanestad BR, Moum T. Fatigue in the general population: A translation and test of the psychometric properties of the Norwegian version of the fatigue severity scale. Scand J Public Health. 2005;33(2):123-130.

103. Anton HA, Miller WC, Townson AF. Measuring Fatigue in Persons With Spinal Cord Injury. Arch Phys Med Rehabil. 2008;89(3):538-542.

104. Sussman S, Holt L, Dent CW, et al. Activity involvement, risktaking, demographic variables, and other drug use: prediction of trying smokeless tobacco. NCI Monogr 1989;(8):57-62.

105. Kalpakjian CZ, Scelza WM, Forchheimer MB, Toussaint LL. Preliminary reliability and validity of a Spinal Cord Injury Secondary Conditions Scale. J Spinal Cord Med 2007;30:131-9.

106. Penn RD, Savoy SM, Corcos D, et al. Intrathecal baclofen for severe spinal spasticity. N Engl J Med 1989;320:1517-21.

107. Priebe MM, Sherwood AM, Thornby JI, Kharas NF, Markowski J. Clinical assessment of spasticity in spinal cord injury: a multidimensional problem. Arch Phys Med Rehabil 996;77:713-6.

108. Csuka M, McCarty DJ. Simple method for measurement of lower extremity muscle strength. Am J Med 1985;78:77-81.

109. Middleton JW, Harvey LA, Batty J, Cameron I, Quirk R, Winstanley J. Five additional mobility and locomotor items to improve responsiveness of the FIM in wheelchair-dependent individuals with spinal cord injury. Spinal Cord 2006;44:495-504.

110. van Hedel HJ, Wirtz M, Dietz V. Assessing walking ability in subjects with spinal cord injury: validity and reliability of 3 walking tests. Arch Phys Med Rehabil 2005;86:190-6.

111. Podsiadlo D, Richardson S. The timed "Up & Go": a test of basic functional mobility for frail elderly persons. J Am Geriatr Soc 1991;39:142-8.

112. Chen CL, Yeung KT, Bih LI, Wang CH, Chen MI, Chien JC. The relationship between sitting stability and functional performance in patients with paraplegia. Arch Phys Med Rehabil 003;84:1276-81.

113. Herdman M, Gudex C, Lloyd A, et al. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). Qual Life Res 2011;20:1727-36.

114. Dittuno PL, Ditunno JF Jr. Walking Index for Spinal Cord Injury (WISCI II): scale revision. Spinal Cord 2001;39:654-6.

115.Schwenk M, Lauenroth A, Stock C, Moreno RR, Oster P, McHugh G, et al. Definitions and methods of measuring and reporting on injurious falls in randomised controlled fall prevention trials: a systematic review. BMC Med Res Methodol. 2012;12:50.

116. Vittinghoff E, McCulloch CE. Relaxing the rule of ten events per variable in logistic and Cox regression. Am J Epidemiol. 2007;165(6):710-718.

117. Bond TG, Fox CM. Applying the Rasch model: fundamental measurement in the human sciences: Lawrence Erlbaum Associates, Inc: Mahwah, NJ, USA, 2001.

118. Lord SR, Allen GM, Williams P, Gandevia SC. Risk of falling: predictors based on reduced strength in persons previously affected by polio. Arch Phys Med Rehabil. 2002;83(6):757-763.

119. Fletcher PC, Hirdes JP. Restriction in activity associated with fear of falling among community-based seniors using home care services. Age Ageing. 2004;33(3):273-279.

120.Cumming RG, Salkeld G, Thomas M, Szonyi G. Prospective Study of the Impact of Fear of Falling on Activities of Daily Living, SF-36 Scores, and Nursing Home Admission. J Gerontol A Biol Sci Med Sci. 2000;55(5):299-305.

121. Matsuda PN, Shumway-Cook A, Ciol MA, Bombardier CH, Kartin DA. Understanding falls in multiple sclerosis: association of mobility status, concerns about falling, and accumulated impairments. Phys Ther. 2012;92(3):407-415.

122. Nilsagard Y, Lundholm C, Denison E, Gunnarsson LG. Predicting accidental falls in people with multiple sclerosis -- a longitudinal study. Clin Rehabil. 2009;23(3):259-269.

123. Friedman SM, Munoz B, West SK, Rubin GS, Fried LP. Falls and fear of falling: which comes first? A longitudinal prediction model suggests strategies for primary and secondary prevention. J Am Geriatr Soc. 2002;50(8):1329-1335.

124. Scheffer AC, Schuurmans MJ, van Dijk N, van der Hooft T, de Rooij SE. Fear of falling: measurement strategy, prevalence, risk factors and consequences among older persons. Age Ageing. 2008;37(1):19-24.

125. Hadjistavropoulos T, Delbaere K, Fitzgerald TD. Reconceptualizing the role of fear of falling and balance confidence in fall risk. J Aging Health. 2011;23(1):3-23.

126.Mann R, Birks Y, Hall J, Torgerson D, Watt I. Exploring the relationship between fear of falling and neuroticism: a cross-sectional study in community-dwelling women over 70. Age Ageing. 2006;35(2):143-147.

127. Kempen GI, Todd CJ, Van Haastregt JC, Zijlstra GA, Beyer N, Freiberger E, et al. Cross-cultural validation of the Falls Efficacy Scale International (FES-I) in older people: results from Germany, the Netherlands and the UK were satisfactory. Disabil Rehabil. 2007;29(2):155-162.

128. Finlayson ML, Peterson EW, Cho CC. Risk factors for falling among people aged 45 to 90 years with multiple sclerosis. Arch Phys Med Rehabil. 2006;87(9):1274-1279.

129. Wannapakhe J, Arayawichanon P, Saengsuwan J, Annatachaya S. Changes of Functional Ability in Patients With Spinal Cord Injury With and Without Falls During 6 Months After Discharge. Phys Ther. 2014;94(5):675-681.

130.McCarney R, Warner J, Iliffe S, van Haselen R, Griffin M, Fisher P. The Hawthorne Effect: a randomised, controlled trial. BMC Med Res Met. 2007;7:30.

131. Saunders LL, Krause JS, DiPiro ND, Kraft S, Brotherton S. Ambulation and complications related to assistive devices after spinal cord injury. J Spinal Cord Med. 2013;36(6):652-659.

132. Nilsagard Y, Denison E, Gunnarsson LG, Bostrom K. Factors perceived as being related to accidental falls by persons with multiple sclerosis. Disabil Rehabil. 2009;31(16):1301-1130.

133. Swedish Meteorological and Hydrological Institute (SMHI). Weather statistics. Available at http://www.smhi.se/klimat/arssammanstallningar/vader/vintern-2014-mild-med-stormig-start-1.36621 [cited 9: th of Dec 2016].

134.Saunders LL, Dipiro ND, Krause JS, Brotherton S, Kraft S. Risk of Fall-Related Injuries among Ambulatory Participants with Spinal Cord Injury. Top Spinal Cord Inj Rehabil. 2013;19(4):259-266.

135.Hoffer MM, Feiwell E, Perry R, Perry J, Bonnett C. Functional ambulation in patients with myelomeningocele. J Bone Joint Surg Am.1973;55(1):137-148.

136. Prosperini L, Fortuna D, Gianni C, Leonardi L, Pozzilli C. The diagnostic accuracy of static posturography in predicting accidental falls in people with multiple sclerosis. Neurorehabil Neural Repair. 2013;27(1):45-52.

137. Deandrea S, Lucenteforte E, Bravi F, Foschi R, La Vecchia C, Negri E. Risk factors for falls in community-dwelling older people: a systematic review and meta-analysis. Epidemiology. 2010;21(5):658-668.

138. Beauchet O, Beauchet A, Beauchet A, Beauchet E, Herrmann FR, Annweiler C. Who is at risk of recurrent falls in "The adventures of Tintin"? (Tome I).J Am Geriatr Soc 2014;(10): 1986-762

139. Mactier K, Lord S, Godfrey A, Burn D, Rochester L. The relationship between real world ambulatory activity and falls in incident Parkinson's disease: Influence of classification scheme. Parkinsonism Relat Disord. 2015;21(3):236-242.

140.Duncan RP, Leddy AL, Cavanaugh JT, Dibble LE, Ellis TD, Ford MP, et al. Accuracy of fall prediction in Parkinson disease: six-month and 12-month prospective analyses. Parkinsons dis. 2012:237673.

141. Hill KD, Flicker L, LoGiudice D, Smith K, Atkinson D, Hyde Z, et al. Falls risk assessment outcomes and factors associated with falls for older Indigenous Australians. Aust N Z J Public Health. 2016; 40(6):553-558.

142.Pinto EB, Nascimento C, Monteiro M, Castro M, Maso I, Campos A, et al. Proposal for a new predictive scale for recurrent risk of fall in a cohort of community-dwelling patients with Stroke. J Stroke Cerebrovasc Dis. 2016:25(11):2619-2626

143.Beauchet O, Dubost V, Revel Delhom C, Berrut G, Belmin J. How to manage recurrent falls in clinical practice: guidelines of the French Society of Geriatrics and Gerontology. J Nutr Health Aging. 2011;15(1):79-84.

144. Allen NE, Schwarzel AK, Canning CG. Recurrent falls in Parkinson's disease: a systematic review. Parkinsons dis. 2013:906274.

145. Flodgren GR, Antoine; Farmer, Andrew J.; et al. Interactive telemedicine: effects on professional practice and health care outcomes. Cochrane Syst Rev 2015 7(9):CD002098

146. Sposaro F, Tyson G. iFall: an Android application for fall monitoring and response. Conc Proc IEEE Eng Med Biol Soc. 2009:6119-22.